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AUTHOR Phelps, William R.
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ABSTRACT

This three-year pilot program provided an opportunity to work intensively with a small group of severe epileptic clients in a comprehensive rehabilitation center setting. The goals of the program were not only to evaluate intensively and attempt to maximize the individual client's potential for working and living in society through the provision of multi-disciplinary services, but also to examine closely the system for providing vocational rehabilitation services in order to determine if the needs of these people might be better served. Through intensive multi-disciplinary evaluation, it was determined that most clients were less handicapped by the occurrence of seizure activity than they were by deficits in the areas of learning, communication, perception, dexterity, interpersonal skills, and, most of all, behavior. Major accomplishments were the documentation of the multiple problems which handicap these people, the development of a method of evaluating these problems through intensive inter-disciplinary programing, the demonstration of the merit of various intervention methods upon behavioral problems, and the formulation of a model in which a comprehensive vocational rehabilitation facility can expand its services. (Author/LRA)

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EPI - LAB

A PROJECT TO VOCATIONALLY REHABILITATE
PERSONS WITH POORLY CONTROLLED EPILEPTIC SEIZURES

FINAL REPORT

West Virginia Division of Vocational Rehabilitation

June 29, 1979

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STAFF

PROJECT DIRECTOR

R. Kent Bowker

PAST PROJECT DIRECTOR

Dennis R. Boggs

PROJECT COUNSELOR COORDINATOR

David K. Steurer

WORK AREA SUPERVISOR

Ethel B. Davidson

SECRETARY/CASE-AIDE

Shirley A. Mullins

PROJECT CONSULTANTS

David A. Clayman, Ph.D - Psychology

T. Pinckney McIlwain, M. D. - Psychiatry

Curtis L. Withrow, M. D. - Neurology

REHABILITATION COUNSELING INTERN

Sara Weaver (part-time)

PAST PROJECT CONSULTANT

9/1/78 to 2/2/79

Marilyn Thatcher - Learning Disabilities

FOREWORD

The following pages contain the results and conclusions of a three year Innovation and Expansion Project which was intended to improve Vocational Rehabilitation programming for a group of persons with severe epilepsy. The usual reporting of program planning, implementation and evaluation efforts is often a stale accounting of numbers and percentages, traits and variables, rationale and explanations. The value of this particular effort will be praised by some and criticized by others, including the clients who were participants.

To make the program, its accomplishments and shortcomings, visible to others is the goal of the report which follows. Somehow the figures, tables and narratives fall short in relating the impact of a program such as this upon the human life. In recognition of this fact, the clients of Epi-Lab were asked to render their impressions of the impact of the program upon their lives. The two (which have been edited only to improve clarity) statements that follow testify not so much to the success of Epi-Lab, but to the strength and courage of two of the persons whom we had the privilege to know during the course of this program.

"Before I went to Epi-Lab, I felt that I was almost totally worthless to everybody. I have had seizures for 21 years and I am 27 years old and for 19 of those years my seizures were the primary focus in my life for me, my parents and brother.

My mother became very protective of me. Since I am a female, I would expect to be protected just because of that fact, but I have been overprotected I feel. My dad and brother would naturally be concerned that I did not hurt myself when I fell and when they saw I hadn't, let me continue with what I had been doing.

With mother it has been a little different. She actually wanted me to wear a football helmet so I wouldn't hurt my head. She first suggested this when I was in grade school and has not given up the hope that I someday will. The last time mom brought up a football helmet was sometime last year, 1978.

Sports and physical activities were practically forbidden to me. At first in high school I thought that was great because I didn't have to take gym and the others did, but that feeling soon grew old and I wanted to be with the rest of my friends and not have to feel like an outcast. The swimming pool is another place I just stopped going to; it was off limits to me and I got to the point that I just didn't ask about it because I didn't want to always defend myself before I was granted permission to go, which wasn't very often.

When I graduated from high school and was allowed to leave home to go to college, I felt really free. I didn't see how I could worry my family much if they couldn't see me and witness my seizures. But in college I ran into different difficulties. I told my roommate that I had epilepsy not controlled by medication. Since she was totally unfamiliar with epilepsy, she moved out of my room the next day so she wouldn't have to deal with something strange to her. That hurt me to know that somebody would reject me that quickly because of my seizures. The rest of the school year went smoothly socially, if not academically. After ----- moved out, ----- moved in and I could not have asked for a better roommate. My second year at college the same thing happened only with a slight difference. The head of the dorm would not assign me another roommate because she did not want the other girl to be responsible for me and the girls on the floor with me kept their distance and didn't like it because I was not the one to leave. My only friends were the girls up the hall that I had met the year before. The Dean of Women asked me to go home and come back when my seizures were cured. So this rejection was worse than before and I went home in about 3 months. I stayed at home 6 years because I knew my family and relatives cared for me and if someone came to our house they already knew I had seizures and I felt safe. But when I was 25 years old and saw no future for myself, I decided it was time to start living and not just existing as I was. It was at that time Epi-Lab was interviewing prospective clients and I found out about it through my doctor and Rehab counselor.

I went to the Rehab Center to give it a try. I remember one of David Steurer's first questions. Why did we choose Epi-Lab and not another hospital? I thought I don't need another hospital to find out that they can't find out what is wrong. I felt I had given hospitals and medication their share of my life and without getting real help to live. I was looking for help to live my life even though I had seizures. So Epi-Lab was really my last hope before giving up totally and finally realizing I was beyond help.

I was in sorry shape when I entered the Epi-Lab program but slowly I started changing. I was beginning to learn that things that I was told I couldn't do, I could do without any major problems. I don't mean to make it sound easy because it wasn't. It was not easy to believe that the things that I had been told for 25 years were untrue and that I had to believe the opposite.

Yes, for once in my life nobody frowned upon my going swimming and without boasting too much, I am a good swimmer. If I had stayed longer I probably could have earned a white cap, lifesaving. I might do it anyway.

It has been a slow process to learn I can live my life like anyone else but I have learned just that.

After being a part, a member, a client of Epi-Lab, I now hold a full-time job - that is something I thought I would never do. I like myself, do not feel like a wrung out dishrag all the time, care about what I look like all the time, want to be part of society, not an outsider, am willing to take risks, look forward to tomorrow, have started living, have met great people. I could keep on going because I now realize that I am no different from the ordinary person except that sometimes I will have a seizure. The fact is really of little importance to me now. Life can be good and everyone has to live with a little inconvenience, some of my inconvenience will be related to my seizures that's all.

Now on my list of priorities, seizures are near the bottom if not the bottom if they are on my list of priorities at all.

I'm not saying Epi-Lab did all of this for me. Epi-Lab made me realize that I could be more than I was and encouraged me. I did the rest myself. Without Epi-Lab and the people that had faith in me, it probably would have taken 10 or 15 years longer before I realized I could do these things, if I ever realized it.

I do not feel that life is passing me by anymore but that I am finally a participant in my own life. I don't have to take what life decides to hand me, usually raw deals. I have the power to refuse or change these things into something more to my liking."

* * * * *

"I have epilepsy. Growing up was hard for me because I was treated differently. I wanted to be like all of the other kids I knew. I liked riding my bicycle with my friends. My parents were afraid I'd have a seizure while I was riding, so they decided that I should get rid of my bike. To them it was a simple decision. To me, it was very confusing. I was denied something that all of the other children took totally for granted.

From the beginning of school, I knew I was "different" from the other children. I didn't understand what an epileptic seizure was. I only knew that I would lose consciousness and later awake feeling groggy and tired. In junior high school I was very much aware that some of my classmates avoided me. I knew it was because I had epilepsy. At first I was hurt, then I was angry. By the time I reached high school I had decided that I didn't need friends. I had tried to make friends many times. I had been rejected many times. From fear of rejection, I became a loner. To others I looked like a happy, attractive, independent girl. In reality I was unhappy, insecure and very lonely.

I entered the Epi-Lab program in October 1977. For the first time in my life I was able to meet and talk with others who shared a common disorder - epilepsy. I had very rarely talked with others about epilepsy. When I met the other clients I felt accepted. I learned that many of them had experienced difficulties similar to mine. We were able to talk to each other and ask questions. As a group we shared experiences and started looking toward the future.

Since I first came to Epi-Lab, the clients have advanced, each of us in a different way. I no longer feel insecure. I realize that epilepsy is not something to be ashamed of. I've made many new friends. I still see apprehension appear when someone hears the word epilepsy. Instead of interpreting this apprehension as a sign of rejection, I take it as an opportunity to explain that epilepsy is only one of many disorders and that there is no reason for fear. It hasn't been easy for me to learn to do this. Many people are afraid of epilepsy because they don't understand it. I've learned that by meeting people halfway, mutual trust and friendship can be achieved.

This is only one way in which Epi-Lab has had a great impact upon my life. I can cope with situations better. I can better understand why people attach fear and apprehension with epilepsy. More importantly, I can better understand myself."

SYNOPSIS

The Epilepsy Project (Epi-Lab' at the West Virginia Rehabilitation Center was a three year pilot program which provided an opportunity to work intensively with a small group of severe epileptic clients in a comprehensive Rehabilitation Center setting. The goals of the program were not only to intensively evaluate and attempt to maximize the individual client's potential for working and living in society through the provision of multi-disciplinary services, but also to closely examine the system for providing Vocational Rehabilitation services in order to determine if the needs of these people might be better served.

During the three year Grant period, 28 adult clients of average intelligence with uncontrolled epilepsy were served in the Epi-Lab unit. Through intensive multi-disciplinary evaluation, it was determined that most clients were less handicapped by the occurrence of seizure activity than they were by deficits in the areas of learning, communication, perception, dexterity, interpersonal skills and most of all behavior. Intensive psychosocial intervention was carried out through all aspects of the program - group therapy, individual counseling, work adjustment, occupational therapy, recreation, etc., toward the goals of enabling each client to maximize his ability to adapt to and cope with life situations in spite of their epilepsy.

Major accomplishments were the documentation of the multiple problems which handicap these people, the development of a method of evaluating these problems through intensive inter-disciplinary programming, the demonstration of the merit of various intervention methods upon behavioral problems, and the formulation of a model in which a comprehensive vocational rehabilitation facility can expand its services for these severely disabled individuals and, thus, have a greater impact upon their overall lifestyle adjustment.

This final report of the Epilepsy Project examines in depth all aspects of the program; the successes, as well as the failures, in an effort to provide to the West Virginia Division of Vocational Rehabilitation and others who work with this population an accurate assessment of all aspects of programming attempted in this innovative project.

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CHAPTER I

STATEMENT OF PROBLEM

BACKGROUND:

The Rehabilitation Act of 1973 (Public Law 93-112) placed emphasis on serving clients considered to be severely handicapped. Epilepsy (if not seizure free for two years) is classified as a severe disability.

The West Virginia Division of Vocational Rehabilitation has been highly interested in serving more effectively those clients with severe epilepsy. However, the Division experienced the same low rate of rehabilitations for persons with epilepsy that has been experienced nationwide for many years. In fiscal year 1972, the Agency rehabilitated 72 persons with epilepsy; in fiscal year 1973, 107; and in fiscal year 1974, 95. The following table gives information as to how West Virginia compared with the remainder of the nation in fiscal year 1972 in number of persons with epilepsy rehabilitated.

	West Virginia	Nation
Total Rehabilitations	7,279	326,138
Rehabilitations of persons with epilepsy	72	4,748
Percent of total rehabilitations made up by persons with epilepsy	1.0	1.5
Rehabilitations of persons with epilepsy per 100,000 population	4.1	2.3

The incidence of epilepsy in West Virginia has been difficult to determine. This disability is not a clear-cut diagnostic entity and is not one of the conditions that must be reported to the State Health Department. Many persons do not disclose their epilepsy because of the social stigma attached to this disability.

The same difficulty in identifying the incidence of epilepsy has been experienced nationwide. The most recent Epilepsy Foundation information (National Commission Report, Volume 1, page 17) estimates that 1% or 2 million Americans have epilepsy. The derived figure for West Virginia is 18,000. These figures include the mild, controlled cases, as well as the severe uncontrolled cases.

A recent survey (Lindberg, 1976) of the prevalence of developmental disabilities in West Virginia found that .35% of the population of West Virginia was "substantially handicapped" by epilepsy. This figure would include the most severe, uncontrolled cases.

In these more severe cases the average age was 25; 48% were 19 and younger, and 72% had attended public school for an average of 7.9 years. Higher rates of epilepsy were found in rural districts in West Virginia.

Other studies which have been conducted in various parts of the United States have been examined but great variability in estimates exists. Thus, for the purpose of program planning in West Virginia, epilepsy must be considered a relatively low incidence disability which heretofore has been underserved.

In planning improved services to a group of severely disabled epileptic clients, the Rehabilitation Agency decided to utilize its multi-disciplinary facility, the West Virginia Rehabilitation Center, as the site in which to attempt intensive and innovative programming. The West Virginia Rehabilitation Center has served persons with epilepsy since its opening in 1955, but severe cases of uncontrolled epilepsy were not served in significant numbers because of inadequate staffing patterns, limited knowledge and expertise, and lack of appropriate programs. However, after adding a neurologist to the staff, the Center amended its policy and permitted clients who were not under good seizure control to enter for pre-vocational and vocational programs.

In order to realize the goal of improving services for persons with epilepsy, the West Virginia Division of Vocational Rehabilitation decided to attempt the initiation of a new program at the Rehabilitation Center for persons of working age with the most severe seizure problems. The idea was funded through a three year Innovation and Expansion project.

The result was the design and implementation of an epilepsy laboratory (Epi-Lab) which was intended to take advantage of the unique aspects of the Rehabilitation Center by providing a wide range of services to the clientele served in the program. The program, its philosophy, and content were developed as a result of combining the knowledge and expertise of all staff and by reviewing resources in the literature which were available prior to program initiation and others which became available during the program itself.

SURVEY OF LITERATURE:

The effects of epilepsy on a person's total lifestyle are all encompassing and often devastating (Bright, 1975, National Commission Report, 1977). When seizures are difficult to control, and all too often even when they are well controlled, problems arise in areas of employment, personal adjustment, physical health, relationships with others, and psychological well-being. Singular approaches to resolving these problems by the helping professions and social agencies often fail because the needs of the total person are not recognized or met. Sometimes these multi-faceted problems are recognized but due to inadequate programming and funding resources, effective efforts are not made.

The recently completed study by the National Commission on Epilepsy (Plan for Nation-wide Action on Epilepsy, 1977) aptly illustrates the many needs of the person with epilepsy and the lack of adequate resources to meet these needs.

Of course, one of the most important areas of concern is employment. It has long been a misconception that the only reasons for unemployment in the epileptic population were employer attitudes and seizure activity. These are factors, but as Rodin (1968) points out, (surprisingly to some) seizure type and frequency are not related to unemployment; rather it is other problems that the epileptic person has to face that are the major reasons for unemployment. Rodin has found that organic mental changes, lowered intellect, and behavioral problems are the three most important difficulties which relate to unemployment. Further evidence in Rodin's (1968) VRA Study illustrates the point more emphatically. In that study statistics revealed that a considerable number of patients with several seizures a week were employed. Those who complain that they couldn't get a job because of their epilepsy were the ones that experienced organic mental changes, lowered intellect, behavior problems, or motivational problems and either were not aware of these deficits or found it easier to blame the seizures.

The Kansas City Study (Shepherd and Gutknecht, 1966) documented the need for and advantages of a multi-disciplinary approach, including a controlled work environment for evaluation of the employment problems of the person with epilepsy. In this Project the significant problems of organic brain damage, mental retardation, behavior and motivation mentioned by Rodin were thoroughly evaluated in a work setting and thus a more accurate and valid prognosis for eventual employment and lifestyle adjustment was made. By becoming aware of the multiple problems of unemployed clients with epilepsy, the authors acknowledged, as did Rodin (1968) that the problem of unemployment was complex and could not be attributed solely to seizure frequency or employer attitudes.

But it can be said that some of the problems which prevent successful employment or lifestyle management can be reduced so that the chances for a more normal lifestyle are increased. This is particularly true in the area of behavior change (Clayman, et. al, 1974).

The behavioral problems of the epileptic person involve his interpersonal relationships, social skills, self-concept, attitude toward others and ability to overcome the negative influences in his life such as the attitudes of society and his adjustment to his seizure disorder. The difference between employed and unemployed groups, successfully adjusted and severely maladjusted people with epilepsy seems to be in their relative level of adaptation to their life situation. This opinion is supported by the recent emphasis on the behavioral aspects of epilepsy (National Commission Report, 1977, Wright, 1975) and the recommendation that the need for group

therapy (Freeman and Gayle, 1977) and other psychological interventions (Wright, 1975; Clayman, et. al, 1974) be considered a critical component in comprehensive programming directed toward the employment concerns of unemployed seizure disordered persons.

Clayman (1974) postulates that the adaptive functioning level that a person with epilepsy achieves is significantly related to his ability to overcome those barriers which prevent successful life adjustment in all areas, including employment, interpersonal relationships and self-acceptance. For example, public attitudes are barriers but to overcome them for personal gain or benefit (e.g., getting a job in spite of seizures), the person must have socially competent behaviors. Many persons with a long history of epilepsy for various reasons (control difficulty, parental over-protection, undue restrictions on lifestyle, etc.) never develop the behaviors (adaptive skills) necessary. Clayman (1974) suggests that persons with poorly controlled seizures develop a lifestyle pattern consisting of a set of behaviors, including seizures, which is non-productive, self-defeating, and maladaptive which limits social and vocational involvement. Frustration and feelings of helplessness resulting from rejections, failures, and disappointments produce stress with which the person cannot cope due to limited adaptive skills. A lowering of self-esteem and tolerance for stress results from continual failures and disappointments and the maladaptive cycle continues with the focus of blame being on the seizures.

Families often reinforce these maladaptive behaviors that Clayman (1974) terms infantilizing, in that the person is treated as if he was not capable (an infant) because he might have a seizure if performing daily functions expected of most competent people.

So the person and his family focus upon the seizure as the cause for all social, vocational and personal failures and the seizure cure is the perceived solution. Thus, the importance of improving adaptive behaviors is critical if overall improvement in lifestyle is to be possible.

In designing the Epilepsy Project at the West Virginia Rehabilitation Center, the Agency took into consideration the importance of behavioral change (Clayman, et.al., 1974) and Wright, 1975) and the unique advantages of a comprehensive Rehabilitation facility (Shepherd and Gutknecht, 1966), but the primary goal of client programming was in interventions in the area of client behavior. It was believed that if client adaptive functioning could be improved, seizure control, self-esteem, independence, social skills, adjustment to disability, and employment potential could also be improved.

CHAPTER II

METHODOLOGY

PROJECT DESIGN

COMPONENTS:

As previously stated, the Epi-Lab Project was designed to utilize the unique multi-disciplinary services available at the West Virginia Rehabilitation Center. The Epi-Lab unit itself had specific programming which was unique, but services were provided by other departments that could not be accomplished within the unit itself.

The methodology employed in the Project was to combine the three full-time staff with consultive staff in psychiatry, psychology, and neurology and work with severely disabled epileptic clients toward goals of evaluation and maximizing of rehabilitation potential.

The programming unique to the Epi-Lab unit itself included:

The Work Area in which observations, evaluations, and interventions in regard to client work-related behaviors were carried out,

Psychological Testing and Groups in which behavioral assessment and interventions in regard to behavioral issues was conducted,

Medical Treatment in neurological clinic where each client was evaluated and treated with anti-convulsant medications, and

Classes during which the medical, attitudinal, vocational and psychological issues of epilepsy were addressed with clients.

Additionally, individual programming was carried out by the full-time staff in problem areas involving cognitive or learning deficits, independent living problems, and other issues.

Programming in other Center departments involved:

Recreation for development of social skills in leisure time activities, improvement of motor skills through recreational training, and increased awareness of importance of leisure activities through leisure counseling.

Occupational Therapy for evaluation and therapy in areas of perceptual motor functioning and daily living skills.

Speech Pathology for evaluation and therapy in regard to communication and learning deficits.

(These services are discussed in greater detail later in this report).

Thus, the entire program had an inter-disciplinary emphasis and a team effort was carried out in attempting to meet client needs. Staff interfacing and communication through formal and informal staffings enhanced the accuracy and benefit of evaluation and intervention by individual disciplines. The details of the staff roles and inter-disciplinary interventions will be discussed in more detail later in this report.

OVERVIEW OF PROGRAM PROCESS:

Efforts in client program planning were organized with a comprehensive flow diagram (See Table 1) which details the program process through which clients progressed during the Project. This comprehensive program process flow diagram facilitated planning and evaluation of specific program areas by enabling more accurate visualization and analysis of problems and accomplishments in each phase of the process. Included, in addition to all client steps from Referral through Program Content to Community Re-Entry and Placement, was the procedure for identification of various types of input, Center staff training activities, and revisions throughout the Project period. The result, an analysis of the procedure and process involved in the development and implementation of the entire program is included in Chapter III of this report.

NOTES ON PROCEEDINGS

BEGINNING DATE:

The Project was funded by The Rehabilitation Services Administration as an Innovative and Expansion Project and began operations on November 1, 1976.

OFFICE AND LOCATION DEVELOPMENT:

The Project was allotted space in the building previously occupied by the Center Recreation Department (See Appendix A). In order to adapt the area to the Project needs, office partitions were constructed, furniture purchased, and supplies ordered. As program planning evolved during the first six months, it was recognized that additional space would be necessary, so a request was made and permission granted to utilize additional space of an adjoining room for the Epi-Lab Work Area. This enabled the Project staff to conduct simultaneous activities with clients in different stages of program completion without interference.

HIRING OF STAFF:

The Project Counselor-Coordinator was employed in the Project on November 1, 1976. He had been involved in the Project for approximately 2 years by participating in the initial planning stages, writing of the Project proposal and exploring in depth the feasibility of including such a Project in the existing Rehabilitation Center structure. The job duties of the Project Counselor-Coordinator included the following:

1. coordinating day-to-day operation of the Project,
2. processing referrals and screening applications,
3. supervising full-time staff and coordinating activities of consultive staff,
4. conducting group and individual counseling sessions with Project clients,
5. coordinating total client services and planning programs for clients after they completed Epi-Lab, and
6. compiling data and coordinating research in evaluation activities.

The Work Area Supervisor was employed in January 1977 and possessed unique qualifications for the position. In addition to attaining an MSW, she had been employed as a social worker, working with the public offender population during which time she was able to develop professional expertise in and personal tolerance for maladaptive behavior. She also possessed those academic and teaching skills necessary to implement programs within the Epi-Lab setting. Her job duties in Epi-Lab included:

1. developing work activities in the Work Area,
2. supervising clients in the Work Area,
3. providing work adjustment services,
4. observing client behavior in Work Area
5. recording seizure activity and other significant behavior observations
6. evaluating the clients' work potential,
7. teaching epilepsy classes,
8. co-leading group counseling sessions, and
9. administering group psychological tests.

The Secretary/Case-Aide brought to the Project clerical experience in a medical setting and familiarity with medical terminology and procedure. Previous experience in the Rehabilitation Center Medical Unit provided her the opportunity for frequent contact with clientele being served in that area. Her strong interest in working with clients and her willingness to assist, as a case-aide, other staff in their direct client-serving roles made her an invaluable member of the team. Her involvement in individual client work, group therapy and group counseling, and in client classes added an extra dimension to the quality of service delivery. Some of her job duties included:

1. acting as receptionist to the unit and performing general clerical functions,
2. organizing and maintaining records and files,
3. assisting with audio-visual and training aids,
4. carrying out individualized special programming with clients on independent living skills,
5. supervising and instructing clients in the Work Area when Work Area Supervisor was unable to be present,
6. assisting professional staff in observations and ratings of clients, particularly in the Work Area, and
7. administering and scoring group psychometrics.

The Project consultants in neurology, psychology and psychiatry were identified in the medical community as persons with a high level of interest and competency in working with persons with epilepsy. The neurological consultant worked for several years at the Rehabilitation Center as staff neurologist prior to becoming associated with the Epilepsy Project. His special interest in seizure patients grew out of his involvement with these persons in his private practice, as well as at the Rehabilitation Center. He expressed a recognition of undeveloped potential within many of these persons and viewed the possible involvement of Rehabilitation in an expanded role in working with these people as a productive step in effecting adequate treatment and control of seizures.

The psychologist was employed through the West Virginia University Medical School, Department of Behavioral Medicine and Psychiatry, by agreement with the Medical School. The psychologist was identified as a person who demonstrated a high interest, considerable experience and professional competence in working with seizure persons. Additionally, his willingness to maintain a high level of involvement in not only client treatment, but also program development, enhanced the contribution that he made to the Project. The job functions of the psychologist included:

1. planning and evaluation of program areas,

2. serving as a consultant to full-time Project staff in regard to behavioral issues,
3. evaluating the psychometric data accumulated on each client,
4. conducting, along with the psychiatrist, group therapy sessions, and
5. analyzing psychometric data on all clients for reporting purposes.

The Project psychiatrist was contracted privately by the Project, though he was functioning as a resident at the West Virginia University Medical School, Division of Behavioral Medicine and Psychiatry during the time of his employment in the Project. He, as did the psychologist, maintained a high level of interest and involvement in all aspects of Epi-Lab programming. The duties carried out in performing his job included:

1. providing initial psychiatric evaluation of each incoming client,
2. conducting group psychotherapy with the psychologist and managing chemotherapy when appropriate.
3. serving as a consultant to Project staff in regard to behavioral issues, and
4. participating in staff training and program planning activities.

Because of his accessibility and willingness, he proved to be a valuable resource person on medical issues beyond the realm of his speciality. His availability for crisis intervention enabled the full-time staff to cope with emergency situations in a more competent manner.

STAFF TRAINING:

During the initial months of the program, considerable time was spent in staff training for both full-time Project staff and other selective Center and field staff. Training activities continued throughout the Project period, with staff, as well as public and professional groups not directly connected with the Rehabilitation Agency.

The full-time staff came to the Project with varying backgrounds and experiences. Skills necessary for working in the Epilepsy Project were developed or sharpened through on-the-job training, workshops, conferences and site visits to other facilities. The Work Area Supervisor and the Case-Aide spent time prior to initiation of client programming in the Center Sheltered Workshop and the Vocational Evaluation unit in order to improve

their knowledge of work behavior observation and assessment, and work adjustment activities. The Project psychologist and psychiatrist conducted a workshop for the three full-time Epi-Lab staff members and 15 other selected Center staff who were to be in direct contact with the Epilepsy Project clients prior to initiation of client programming. The workshop was designed to assist these key staff in becoming more comfortable and capable in handling seizure episodes so they could serve as models for other staff. It was also intended to assist the staff in understanding and gaining insight into their own attitudes toward this severely disabled population.

The full-time staff visited several facilities with exemplary epilepsy programs including Colin Anderson Center for the Mentally Retarded which housed a recently completed seizure control project sponsored by the Developmental Disabilities Council and West Virginia University Medical School.

A visit was also made to Epi-Hab, Evansville, Indiana and the Tri-State Epilepsy Association, Evansville, Indiana.

A least one of the full-time Project staff attended every Epilepsy Foundation of America national conference during the three years, as well as every conference on epilepsy sponsored by the Mountain State Epilepsy League or the Developmental Disabilities Council in West Virginia during the Project period.

The results of training efforts have been many. As staff knowledge and experience increased, comfort and knowledge in working with epileptic clients improved.

Of course, considerable knowledge was gained through the daily contact with clients in Epi-Lab and the concurrent and continual evaluation of program content and methodologies. As a result of this daily experience, the staff was considered to be much more capable in working with this population at the conclusion of the Project than they were at the beginning.

Major improvements were in the areas of handling seizure episodes, managing maladaptive behavior, understanding and correcting manipulative client behaviors, observing and evaluating client skill deficits, and counseling with the epileptic client.

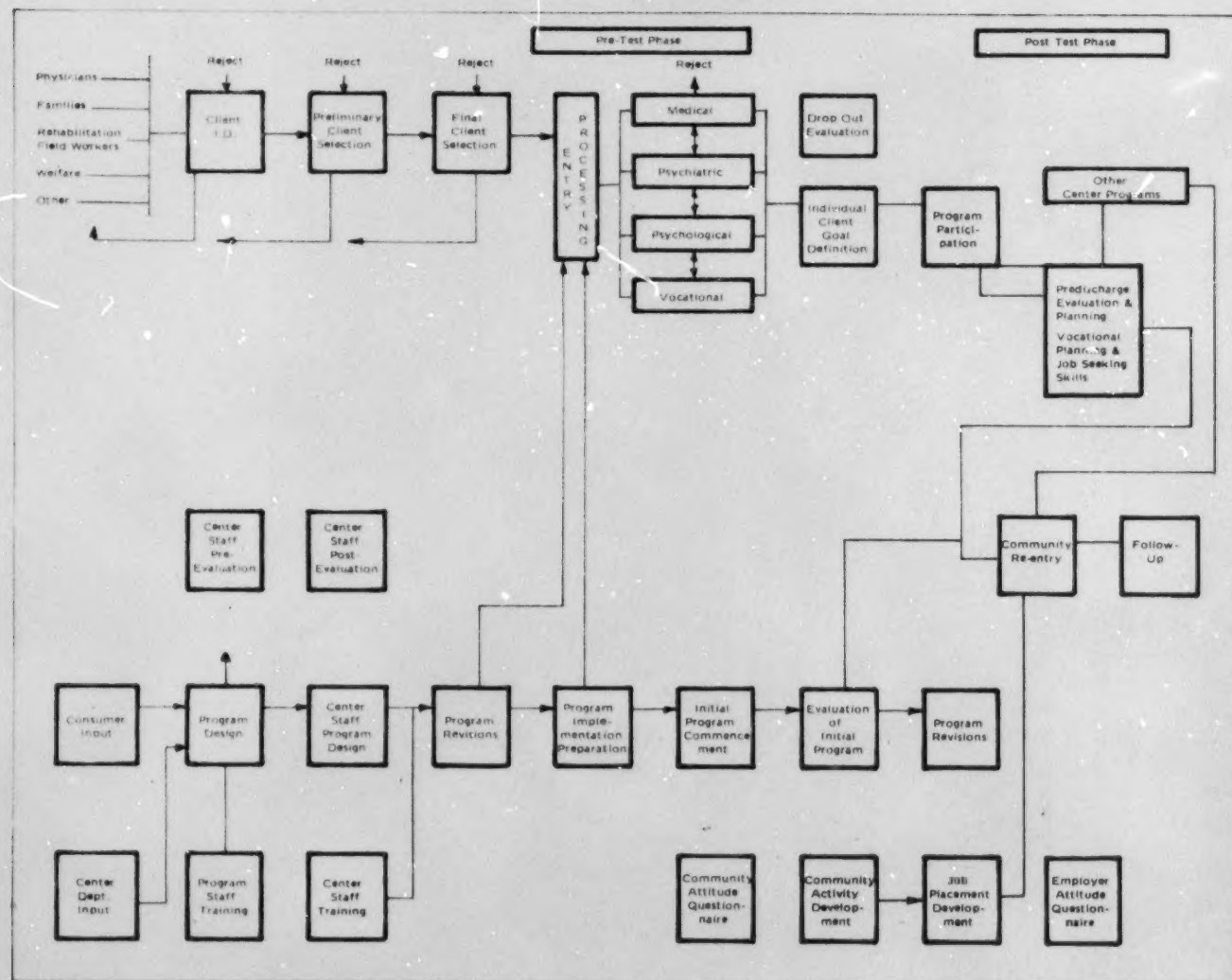
Training of other Center and field staff was also accomplished during the Project period. As the Epi-Lab staff improved in its knowledge of epilepsy, this knowledge was shared through several conferences and informal programs during the Project period. Prior to the initiation of the client service program, anticipating considerable anxiety and resistance by other Center staff, a Center-wide workshop was conducted by the Epi-Lab staff on April 12 1977, on the subject of epilepsy (See Appendix B). During this workshop, the consultants discussed the medical and historical aspects of epilepsy, as well as the Project philosophy and

program direction. The session provided didactic information about epilepsy to Center and field staff, and also attempted to elicit support of the staff for the Project effort. A significant attempt was made to address the staff's concern in regard to their expectations of disruption and increased involvement by the medical staff in handling frequent seizure episodes.

Additionally, in the process of securing referrals to the Project, the Epi-Lab staff designed a slide presentation and brochure intended for use by field counselors and prospective clients, informing them of Project content, as well as general information about epilepsy. The brochures were distributed statewide within the Agency, as well as to other social agencies and the slide presentation was viewed by counselors in four districts throughout the state, as well as by other professional, student, and lay groups.

The Project staff participated in many other training activities designed to impact upon the general public, as well as other professionals working with people with epilepsy. These efforts are detailed in Appendix C.

TABLE I



CHAPTER III

PROGRAM PROCESS

During both the program planning and implementation phases of Epi-Lab, an effort was made to be constantly aware of each component part of the program process. Methodology, procedures, and content of the program were planned, designed, tried, modified, and revised through experience in the program. A close analysis of the various program process components will contribute to knowledge of all aspects of Epi-Lab as it touched the lives of many persons with epilepsy. The process is illustrated in the flow diagram (Table 1).

PROGRAM DESIGN

In the preliminary design phases of Epi-Lab, input was sought from consumers, Vocational Rehabilitation field staff, Rehabilitation Center client serving and administrative staff, and other agencies and professions serving the population. Also, the literature on epilepsy was surveyed and site visits were made to other facilities serving people with epilepsy. Communication with other known epilepsy facilities and programs outside this state contributed to the staff's awareness of other programs, their accomplishments and difficulties.

Consumer input was limited in the initial planning stages, except from the Epilepsy Foundation of America which supplied, in response to a request, pre-printed materials and references. The local chapter of the Epilepsy Foundation of America had very few consumer members and their input was not significant in the initial stages. However, consumer input increased dramatically when client services began. The staff requested and received many ideas and recommendations from clients served in Epi-Lab as to how their needs were being met. Many of their ideas were incorporated into program changes as the Project evolved.

Most programs for people with epilepsy that were reviewed were found to be either primarily medical control programs for severe intractable epileptics, or counseling and placement-oriented Vocational Rehabilitation programs for persons with good seizure control and good job potential. However, many ideas were gleaned from these sources and these were included in some areas of program content.

A major source of input came from Center and Agency staff through questionnaires, attitude surveys, and training sessions. The Vocational Rehabilitation staff was vocal about their problems in working with epileptic clients and Center staff had many apprehensions relative to the increased number of uncontrolled seizure clients which would be coming to the Center. These concerns were addressed in various training sessions described elsewhere in this report.

The most concentrated planning effort was made by the Project staff. The planning role of the psychiatrist and psychologist was significant and quite a departure from the traditional patient-treatment only role which is typical in the Rehabilitation Center setting. The planning sessions, prior to initiation of client services, were directed toward examining every phase of the processing of clients through the program from Client Identification to Job Placement and outlining procedures to be followed and possible solutions to anticipated problems. Primary emphasis was in the area of Program Participation and other in-Center phases of the program. Even though considerable planning was carried out prior to initiation of client services, revisions and changes were found to be necessary as the Project developed during the Project period. These changes will be described in the sections which follow in this portion of the report.

CLIENT IDENTIFICATION:

Identification of potential clients for Epi-Lab required extensive effort in many areas. The process of securing referrals and screening in the most appropriate and with the highest potential to benefit was a constant area of concern and never achieved satisfactory resolution.

Initial efforts to identify prospective clients for the Project preceded Project initiation. In order to estimate the number of clients that might benefit from the Project a survey was made of the West Virginia Rehabilitation counselors in regard to their knowledge of epileptic clients with severe problems in their respective territories. Approximately 180 clients were identified in that survey.

The initial in-Agency request for referrals was in the form of a Director's Letter (See Appendix D) which not only provided the Agency policy statement governing client selection, but also presented to all Agency field counselors a description of the program purposes and guidelines for client selection. Additionally, progress reports were provided to Agency staff through articles in the Staff Bulletin (See Appendix E). Potential referral sources outside of the Agency were also viewed as important areas of concentration in referral efforts. Telephone and written contact was made with other agencies such as the Veteran's Administration, Department of Crippled Children's Services, Department of Welfare, and to private neurologists in the Charleston area informing them of the new Center Project and requesting their assistance in identifying persons with severe seizure disorders who might benefit from this type of program.

In spite of these efforts to secure referrals, the Project continued to experience a lack of adequate and appropriate referrals. Thus, additional efforts to publicize the Project and secure names of potential clients were made and include the following:

1. Publication and distribution of the Epi-Lab brochure to various social agencies, physicians, clinics, etc. throughout West Virginia was carried out.
2. A slide-tape presentation was developed and presented to the field counselors in three of the largest districts in West Virginia describing problems of people with epilepsy in general and presenting details of Epi-Lab programming for this population.
3. A letter was written by the psychiatric consultant to all neurologists in West Virginia explaining the program and asking for referrals (See Appendix F).
4. The Epi-Lab Advisory Group members made contacts within their respective agencies to promote the program and secure referrals.
5. Visits were made to the Department of Crippled Children's Services seizure clinics in order to identify prospective clients.
6. Articles were published in various publications within the rehabilitation Agency and in the State Medical Journal (See Appendix G) to promote the Project and increase awareness of staff who could refer.
7. A survey of all Agency field counselors was made in order to assist them in identifying clients in their caseload with epilepsy-related problems who might be able to benefit from Epi-Lab services. (See Appendix H). This was accomplished after review and screening of all clients with epilepsy on the Agency Master List.
8. Staff became involved in the Mountain State Epilepsy League and presented several programs with that organization while at the same time asking for referrals.

The results of the effort to identify potential referrals are summarized in Tables 2 through 6. A review of this data reveals some interesting points including:

1. Only 131 names became known to Epi-Lab in 2½ years of efforts to secure referrals (See Table 2). Of these, 111 (85%) came from within the vocational rehabilitation Agency (field counselors, Center counselors, Screening Committee). Evidently, public relations efforts had little effect.
2. Of the total names (See Table 2) referred, 40 (31%) were accepted into the program and 31 (24%) entered Epi-Lab. (28 for the whole program, 3 for selected parts only).

TABLE 2
PERSONS WITH EPILEPSY
IN CONTACT WITH EPI-LAB
(N=131)

	Total	Percent
Overall Referrals	131	100%
Type of Referral		
Name only	53	40%
Name and case	25	19%
Name and tour	16	12%
Name-Case-Tour	37	28%
Referral Source		
Field counselor	92	70%
Center counselor	13	10%
Center Screening Committee	6	5%
CAMC-Behavioral Medicine	4	3%
DCCS	2	2%
M. D.	9	7%
DOW	1	.8%
Family	2	2%
Legal aid	1	.8%
DMH	1	.8%
Action		
Accepted - entered program	31	24%
Accepted - did not enter	9	7%
1. client refused	6	5%
2. sent to other program	1	.8%
3. went to work	2	2%
Total accepted	40	31%
Rejected		
1. Mentally retarded	13	10%
2. Psychiatric	6	5%
3. Psychiatric (violent)	2	2%
4. Drug problems	1	.8%
5. Mentally retarded and psychiatric	2	2%
6. Medical problems	8	6%
7. Mentally retarded, medical, and psychiatric	1	.8%
8. Age	2	2%
9. Age - other medical problems	1	.8%
10. Controlled	6	5%
11. Controlled - no medical problems	2	2%
12. No behavior problems	1	.8%
13. Controlled - no behavior problems	1	.8%
14. Mentally retarded - no behavior problems - controlled - working	1	.8%
Total rejected	47	36%

No Action or Decision Necessary		
Held	1	.8%
No interest by client	8	6%
Case closed in field	5	4%
No follow-up by referral source	17	13%
No action needed (consult only)	4	3%
Sent to other Center program	6	5%
Field counselor decided not to refer	3	2%
Total No Action	44	34%

TABLE 3
CONTACTS WITH NAME ONLY
(Primarily Phone Inquiries From
Counselors, Doctors, and Other
Social Agencies)
(N=53)

	Total	Percent
Referral Source		
Field counselor	31	58%
Center counselor	5	9%
Screening Committee	6	11%
CAMC - Behavior Medicine	1	2%
DCCS	2	4%
M. D.	5	9%
DOW	1	2%
Family	2	4%
Legal aid	0	
DMH	0	
Action		
Accepted - entered program	0	
Accepted - did not enter program	0	
1. client refused		
2. sent to other program		
3. went to work		
Total accepted	0	
Rejected		
1. Mentally retarded	5	9%
2. Psychiatric	1	2%
3. Psychiatric (violent)	1	2%
4. Drug problems	0	
5. Mentally retarded and psychiatric	1	2%
6. Medical problems	3	6%
7. Mentally retarded, medical, and psychiatric	1	2%
8. Age	1	2%
9. Age - other medical problems	0	
10. Controlled	3	6%
11. Controlled - no medical problems	1	2%

TABLE 3 (cont.)

12. No behavior problems	0	
13. Controlled - no behavior problems	0	
14. Mentally retarded - no behavior problems - controlled - working	0	
Total Rejected	17	32%
No Action or Decision Necessary		
Held	0	
No interest by client	7	13%
Case closed in field	3	6%
No follow-up by referral source	13	25%
No action needed (consult only)	4	8%
Sent to other Center programs	6	11%
Field counselor decided not to refer	3	6%
Total No Action	36	68%

TABLE 4

CONTACTS WITH INFORMATION
REGARDING NAME AND CASE HISTORY
(N=25)

	Total	Percent
Referral Source		
Field counselor	22	88%
Center counselor	1	4%
Screening Committee	0	
CAMC - Behavioral Medicine	0	
DDCS	0	
M. D.	0	
DOW	0	
Family	0	
Legal Aid	1	4%
DMH	1	4%
Action		
Accepted - entered program	0	
Accepted - did not enter		
1. client refused	2	8%
2. sent to other program	1	4%
3. went to work	0	
Total Accepted	3	12%
Rejected		
1. Mentally retarded	6	24%
2. Psychiatric	4	16%
3. Psychiatric (violent)	0	
4. Drug problems	0	
5. Mentally retarded and psychiatric	1	4%
6. Medical problems	3	12%

7. Mentally retarded, medical, and psychiatric	0	
8. Age	0	
9. Age - other medical problems	0	
10. Controlled	2	8%
11. Controlled - no medical problems	0	
12. No behavior problems	1	4%
13. Controlled - no behavior problems	0	
14. Mentally retarded - no behavior problems - controlled - working	0	
Total Rejected	17	68%
No Action or Decision Necessary		
Held	1	4%
No interest by client	0	
Case closed in field	2	8%
No follow-up by referral source	2	8%
No action needed (consult only)	0	
Sent to other Center programs	0	
Field counselor decided not to refer	0	
Total No Action	5	20%

TABLE 5

CONTACT WITH NAME AND
POTENTIAL CLIENT TOURING EPI-LAB
(N=16)

	Total	Percent
Referral Source		
Field counselor	11	69%
Center counselor	3	19%
Screening Committee	0	
CAMC - Behavioral Medicine	2	13%
DCCS	0	
M. D.	0	
DOW	0	
Family	0	
Legal Aid	0	
DMH	0	
Action		
Accepted - entered program	2	13%
Accepted - did not enter		
1. client refused	1	6%
2. sent to other program	0	
3. went to work	1	6%
Total Accepted	4	25%
Rejected		
1. Mentally retarded	2	13%
2. Psychiatric	1	6%

TABLE 5 (cont.)

3. Psychiatric (violent)	1	6%	Screening Committee	0	
4. Drug problem	0		CAMC - Behavioral Medicine	1	3%
5. Mentally retarded and psychiatric	0		DCCS	0	
6. Medical problems	1	6%	M. D.	4	11%
7. Mentally retarded, medical, and psychiatric	0		Action		
8. Age	0		Accepted - entered program	29	78%
9. Age - other medical problems	0		Accepted - did not enter		
10. Controlled	1	6%	1. client refused	3	8%
11. Controlled - no medical problems	1	6%	2. sent to other program	0	
12. No behavior problems	0		3. went to work	1	3%
13. Controlled - no behavior problems	1	6%	Total Accepted	33	89%
14. Mentally retarded - no behavior problems - controlled - working	1	6%	Rejected		
Total Rejected	9	56%	1. Mentally retarded	0	
No Action or Decision Necessary			2. Psychiatric	0	
Held	0		3. Psychiatric (violent)	0	
No interest by client	1	6%	4. Drug problem	1	3%
Case closed in field	0		5. Mentally retarded and psychiatric	0	
No follow-up by referral source	2	13%	6. Medical problems	1	3%
No action needed (consult only)	0		7. Mentally retarded, medical, and psychiatric	0	
Sent to other Center programs	0		8. Age	1	3%
Field counselor decided not to refer	0		9. Age - other medical problems	1	3%
Total No Action	3	19%	10. Controlled	0	

TABLE 6

CONTACTS WITH POTENTIAL CLIENT
TOURING EPI-LAB AND
CASE HISTORY REVIEWED
(N=37)

	Total	Percent
Referral Source		
Field counselor	28	76%
Center counselor	4	11%

11. Controlled - no medical problems	0	
12. No behavior problems	0	
13. Controlled - no behavior problems	0	
14. Mentally retarded - no behavior problems - controlled - working	0	
Total Rejected	4	11%
No Action or Decision Necessary		
Held	0	
No interest by client	0	
Case closed in field	0	
No follow-up by referral source	0	
No action needed (consult only)	0	
Sent to other Center programs	0	
Field counselor decided not to refer	0	
Total No Action	0	

3. A great majority, 29 (78%) of the clients who had the benefit of a tour, and for whom a case history was made available entered the program (See Table 6). This points to the value of spending extra time in orienting and educating prospective clients about a new program which is difficult to understand, as well as the value of making background information available to staff screening candidates for the program.

4. Potential clients rejected totaled 47 (36%), (See Table 2). The major reasons for rejection were mental retardation 13 (10%), other severe medical problems 8 (6%), severe psychiatric problems 6 (5%), and seizures under complete or good control 6 (5%).
5. Most rejections were made because clients did not meet Project criteria. Most of the reasons were due to overriding problems in the areas of mental deficiency, psychiatric illness, or other severe medical problems such as severe cerebral palsy, organic brain syndrome, etc. that was the primary disabling condition. The screening process always attempted to identify the primary cause of the client's problem in relation to epilepsy or associated problems. This was due to the fact that the purpose of the Project was to study epilepsy.

Many other interesting analyses could be obtained from the referral information. The most important fact of this analysis is that the clients who were accepted were well oriented to the Project having toured the unit and met the staff prior to entry, and were appropriate in terms of meeting selection criteria and experiencing their problems because of their epilepsy. Though the tables do not indicate this statistic, it is known that of 29 clients who were actually scheduled for full-time Epi-Lab service, only one did not enter the program. The other 28 fulfilled their commitment by entering the program.

PRELIMINARY CLIENT SELECTION:

Client identification, as discussed in previous paragraphs, was made on the basis of very general criteria specifying that prospective Project clients were those persons of working age with average intelligence who were experiencing problems with frequent seizures. The stage of preliminary client selection defined more specific criteria in order to select clients who were most appropriate for the Project. The specific client characteristics were as follows:

1. The medical diagnosis of epilepsy must have been definite and supported by recent EEG, x-ray, or other clinical evidence.
2. Intelligence quotient must have been 80 or above (based upon WAIS full scale or other measure such as Beta or Slosson instruments).
3. Seizures must have been uncontrolled. This factor was variable in terms of number of seizures within specified time period. However, evidence must have indicated that client was severely hindered in functioning due to seizures or related problems.

4. There must not have been a significant secondary disability such as cerebral palsy, mental retardation, or hemiparesis.
5. Client had to be at least 18 years old.

The information requested from the referral source (the field counselor) included the following:

1. A complete medical work-up must have been completed in order that the nature of specific seizure and related problems was well defined and documented.
2. Referral information must have also included documentation of problems in employment, family and educational settings. These problems must have related primarily to the seizure disorder and not to a secondarily disabling condition.
3. Other information such as psychological and educational records, work history, and routine Vocational Rehabilitation data were also requested to complete the referral information.

Evaluative efforts in preliminary client selection sought to differentiate between the "accepted" and "hold" groups of clients.

The actual screening of the cases was accomplished by varying procedures as the Project evolved, but the final procedure was as follows:

Case files were compiled by the field counselor (even if initial referral was made from outside the Agency) and submitted to the Project Coordinator for review. The Project Coordinator, utilizing the data form (See Appendix I), screened the file to insure that it met the initial selection criteria. Then the case was circulated to the Project psychiatrist and psychologist and to the neurologist and Work Area Supervisor on occasion. Each staff member who reviewed the case evaluated it and recommended acceptance, rejection, or hold on the Case Review Form (See Appendix J). If two of the three staff reviewing the case recommended acceptance, the case was accepted and the field counselor and client notified of the fact. The client's name was placed on the waiting list for Epi-Lab and the Center Registrar notified with regard to date of call-in.

The next step was to encourage the prospective client to visit the Center (if he had not already done so). A letter was sent to him directly informing him of his acceptance and asking him to tell the staff, in writing, his understanding of the purpose of Epi-Lab and what he hoped to accomplish by participating in the program.

The primary problem encountered in this phase of the program

involved the extreme difficulty which was experienced in maintaining high standards for medical and psychological information. Many files were incomplete and contained conflicting information regarding the client's seizure diagnosis, frequency, and other essential data. In several cases, clients were found to be experiencing quite different situations in regard to their seizure activity than was documented in the case. Additionally, many valuable work-ups accomplished in major medical centers were impossible to obtain. Thus, in many cases the Center staff was forced to begin with inadequate information and repeat much of the evaluation procedures which had been previously accomplished prior to Center entry.

FINAL CLIENT SELECTION:

The final selection of clients who entered the Epi-Lab Project were those that met the medical, psychological, vocational, and other standards set forth by the Project staff and consultants. It is noteworthy that of the 28 clients who entered the full time program, 27 had the benefit of an individual interview and tour of the Epi-Lab and the Rehabilitation Center facility prior to entry (See Table 6). Pre-entry program explanations which were usually made during the tour were standardized for all prospective clients in order to minimize misconceptions and misunderstandings in regard to expectations or program content and client goals.

Pre-entry program explanations contained the following information:

1. An explanation was made of the purpose of the program in thoroughly evaluating the client for seizure problems, vocational possibilities, behavior problems, and other significant problems in his life.
2. The goals of the program were explained in terms of assisting each client in reaching his maximum potential in medical control, personal adjustment, independence, and work ability. Vocational goals were only one of the possible goals mentioned to the client. A concerted effort was made not to mislead the clients into believing that they were coming to the Project solely for vocational preparation, for it was anticipated that many clients would not be candidates for training or employment unless considerable improvement was made in problem areas.
3. The routine of daily activities was thoroughly explained including work activities, classes, group discussions, group counseling, recreation, tests, medical exams, etc.
4. The importance and nature of contracting and contract compliance were explained to the prospective clients. They were also told that they would be required to reside during the week in the Center dormitory, and that

the time period involved in the Project would be determined on an individual basis, but would probably be 3-6 months.

5. Also, specific mention was made of the importance of complying with the Center standards of behavior, especially refraining from any violent behavior, and complying with medical instructions (e.g., taking medicine as prescribed, etc.).
6. Client participation and involvement in program evaluation was emphasized and the staff insured that clients understood that the Project was an experimental effort to provide a program of services to persons with severe seizure disorders.

Problems developed with the first group of clients in regard to the completeness of their understanding of the program and its application to each individual case. Therefore, revisions were made so that contracting terms were more specific in the area of family interaction, compliance with medical instructions, identification of goals beyond seizure control, and individual client motivation (as opposed to family pressure) for program participation. A significant aspect of this phase which deserves a more detailed treatment is the tour which proved highly successful in providing clients with the motivation and orientation to successfully enter the program. Several aspects of the client tour are viewed as critical:

1. Tours helped erase misconceptions that clients held about Epi-Lab and the Rehabilitation Center. Some of the common misconceptions included the Epi-Lab and Rehabilitation Center were a repressive, restrictive, "institutional", environment; the food was bad; negative reactions would be experienced when encountering other severely handicapped people; fear of other epileptic clients, etc.
2. Tours helped to motivate clients for, after seeing other disabled clients, they often gained the perspective that others were in "worse shape" than they were or that others had similar problems that were not insurmountable. Also, the Recreation area, with its many activities which were not available to many of these clients in their home area, served as an attractive selling point for the Rehabilitation Center.
3. The tours enabled the clients to become acquainted with the Epi-Lab staff so that when they reported for the program they had overcome some of the initial anxiety that is often associated with the unknown. They also were able to acquire answers to important questions from the staff, so that they were not misled by inadequate information about the program. It was believed that a trusting relationship developed

between the staff and many clients as a result of the positive initial contact during the client tour.

4. It was noted that touring a specific program rather than the entire Center, which would include the training areas, the Sheltered Workshop, the medical unit, etc., reduced the client confusion and misconceptions in regard to the program for which he was being considered. This has been of particular concern to clients coming for pre-vocational programs such as Epi-Lab when a vocational goal is not of immediate concern, but rather pre-vocational objectives which may eventually lead toward the definition of a vocational goal are emphasized.

The last step in the final client selection involved the contacting of the client three weeks prior to entry date by the Center Registrar. The "call-in letter" provided the client with essential information regarding when to report, where to report, what to bring, etc.

ENTRY PROCESSING:

Entry processing into the Rehabilitation Center and Epi-Lab involved the orientation and adjustment of the new clients to the physical environment of the Rehabilitation Center, as well as to the philosophical orientation and screening by various disciplines involved in their program during these initial phases.

The clients reported to the Rehabilitation Center on Sunday and were incorporated in an orientation schedule with new students coming not only for Epi-Lab, but also other Center services. During the first two days, Monday and Tuesday, the clients, along with the other new students, were assigned to dormitory rooms, provided an initial orientation to the Center, as well as a tour, advised of rules and regulations governing Center activities, and screened by the Medical Clinic, Dental Clinic, Speech and Hearing Clinic, etc.

The clients' first contact with the Epi-Lab program as students occurred on Monday morning at 10:00 a.m. during a break in the new student orientation routine. During this period of time, the three full-time staff provided an orientation for the new students to Epi-Lab, stressing the following topics:

1. Epi-Lab as a Project - The students were informed of the experimental nature of the program and an attempt was made to elicit their cooperation in undergoing frequent psychological examinations and assisting in the collection of information regarding their seizure behavior and other items of concern. They were made fully aware of the goals of the Project, in that it was designed to learn more about the problems of all people with epilepsy. They were encouraged to provide the staff with feedback and information regarding program effectiveness and were told

to express their needs and feelings to staff so that a greater understanding of their seizure disorder and its associated problems could be obtained.

2. Structure of Epi-Lab - The students were introduced to the staff and the role and function of each staff member was explained to them.
3. Program Components - The various aspects of the program were fully explained from initial orientation, evaluation (testing, medical exams, Work Area, etc.) activities, through Work Area programming and use of other Center services such as Recreation, Occupational Therapy, and Speech Pathology.
4. Philosophy of Epi-Lab - The accepted policy (See Appendix K) for handling seizure episodes at the Rehabilitation Center was explained. The students were told that the program philosophy did not place emphasis upon seizure control alone, although that was an important goal. Instead stress was upon development of a totally competent person who could deal with the world in the best manner possible, depending upon individual potential. Seizures were not to be viewed as a medical emergency, but would be handled appropriately on an individual basis in accordance with Center procedure. They were also informed that one of the program goals for every client was to assist them in focusing away from their seizures and to other more positive aspects of their personalities which could be used productively in achieving a more satisfactory adjustment to life. In this manner, the concept of behavior and attitude change was introduced.
5. Program Goals - The program philosophy regarding behavioral objectives was discussed with the clients. An attempt was made to assist them in understanding the importance of concentrating upon personal behavioral goals prior to considering vocational planning. Issues in regard to public attitudes and societal prejudice were often brought up by the students. It was again stressed that personal change and becoming the most competent person possible was the most productive way to advocate and effect change in one's personal situation.
6. Contracting - Making a strong commitment to oneself and to the program was emphasized. Explanations in regard to staffing procedure and outlining of program goals was also presented to the clients.
7. Adjustment to Center - The importance of becoming satisfactorily adapted to the Rehabilitation Center was emphasized as being a primary goal of the first week prior to intensive program involvement. Also, because of the tendency for clients in special programs to

become isolated from other clients, they were encouraged to consider themselves to be Center students, as well as Epi-Lab students and to participate in other Center-wide social and recreational activities.

On Wednesday morning after the students completed their activities with other Center students, they were permanently assigned to the Epi-Lab. The first week of Epi-Lab activities primarily involved screening and evaluation activities designed to establish baseline information on seizure activity, psychological profiles, motivation, attitude, work habits, etc. The following activities comprised the Epi-Lab activities during the first two weeks:

1. Counseling Interview - An individual counseling interview was conducted with each client for the purpose of establishing a counseling relationship, securing biographical and demographic information for data collection purposes, formalizing the Rehabilitation plan initiated by the field counselor for Epi-Lab services, and answering the individual questions and concerns of each client.
2. Group Psychometric Testing - All incoming clients were tested with a standard battery of psychological tests which were later interpreted by the psychologist following administration of the Weschler Adult Intelligence Scale. The battery was composed of the following instruments:
 - a. Wide Range Achievement Test
 - b. Bell Adjustment Inventory
 - c. The MMPI-CPI
 - d. The Tennessee Self-Concept Scale
 - e. I-E Scale
 - f. The Mooney Problem Checklist
 - g. The 16 Personality Factor Questionnaire
3. Psychiatric Examination - Every client was seen individually by the Project psychiatric consultant. (Please refer to the Medical Section of this report for further explanation in regard to the purpose and procedure involved in this activity.)
4. Neurological Examination - All entering Epi-Lab clients were referred to the Center Neurology Clinic. Examinations were performed when necessary. However, when a recent examination had been completed by the client's personal neurologist or physician, and when adequate

information was available, the Project neurological consultant reviewed the records and made recommendations in regard to a treatment plan for the client during his Center stay.

5. Vocational (Work Area) Assessment - After the clients completed all other aspects of their orientation and screening, they were oriented to the Epi-Lab Work Area and participated in initial work activities for a period of 1 week. The details of this procedure are contained in the Work Area Supervisor's Summary on page 42.

It is significant to note that all screenings were intended to identify initial client problem areas, as well as strengths, and to develop contract terms and program goals toward which the client would strive while in the Epi-Lab program. Throughout the initial phase of this two week orientation process, the clients were introduced gradually to the Epi-Lab's philosophy of seizures and to the idea of achieving personal and behavioral goals rather than complete seizure control.

Following the first two weeks of orientation, screening, and evaluation, a staffing was conducted by the Project staff, sometimes including the consultants and at all times the client. The purpose of the staffing was to inform the client of the results of the initial two week assessment and to define program goals for the remainder of his program. The client was encouraged to participate fully in the staffing by expressing his goals, reactions to staff recommendations and opinions, and also how he planned to utilize the program to reach his goals. The effectiveness of future programming was viewed as being determined by the degree to which the client understood and became committed to goals established in the staffing. After discussing various alternatives with the client and agreeing upon program goals, the Project Counselor-Coordinator completed the contract form (See Appendix L), a copy of which was given to the client. This document served as the focal point of all programming during the next portion of the client's program.

As might be expected, the process of initiating client programming in the entry processing phase did not, in reality, transpire as smoothly as might be expected from the above description. Many problems occurred, some of which were unique to individual clients and some of which were characteristic of the population. Some of the more significant problems were as follows:

1. In some cases frequent seizure episodes or medication side effects such as extreme drowsiness, incoordination, disorientation, etc., prevented a client from gaining the most benefit from the orientation and being able to participate in it fully. Therefore, in some cases even after the two week orientation period, orientation activities for clients experiencing these types of difficulties were ongoing throughout the program phase. In

a few isolated cases, some clients never did understand what the program was all about. The reasons for this are discussed in other sections of this report. (See Work Area, page 37; Learning Disabilities, page 75).

2. Due to many factors, some clients were extremely slow in completing orientation activities, especially psychometric testing. The orientation, screening, and psychometric evaluation was intended to last one week and was expanded to two because of the lengthy period of time it took most clients to complete the routine.
3. In spite of intensive initial efforts to orient clients to behavioral objectives and to concerns other than their seizures, it was common for them to focus entirely upon their own seizures and those of others and judge staff effectiveness and concern for them on the basis of reactions to seizure episodes. Often unrealistic and unnecessary treatment was expected and when it was not received, animosity toward the staff increased beyond that which was already present.
4. As is mentioned elsewhere in this report, many clients were extremely hostile during the initial phases of their program. This hostility and anger was viewed as an expression of general frustration in response to the clients' individual life situations and the inability of previous programs and treatments to "cure" their seizures. These strong emotions reinforced false expectations of the program, the staff, and the Center, and prevented understanding of and adherence to program philosophy and methodology. Much time was lost with some clients in dealing with these projected emotions. Those clients who did not have this problem were often able to improve more quickly if they were not influenced or dominated by their hostile peers.
5. As previously stated, the orientation stressed the concentration on pre-vocational, behavioral goals and not vocational goals. However, because the clients were participating in a program which was based in a Vocational Rehabilitation Center where the majority of students were in vocational training, the issue of identification of a vocational goal was a difficult one to avoid and postpone. Most clients were interested in determining, as soon as possible, the type of vocational training or job they would be working toward irregardless of the severity of their problems and in spite of staff efforts to assist them in concentrating on psychological or behavioral goals which were viewed by staff to be critical to vocational success.
6. Contract compliance was also less than desirable. In spite of client verbal and written agreement to work

toward goals specified in individual contracts, significant gaps existed in understanding of and compliance with these individualized objectives. Efforts to reinforce contract goals were made in individual counseling sessions, group session, epilepsy classes, supervisory activities in the Work Area, and informally. In spite of these efforts, however, most clients had difficulty addressing in a productive manner the goals of their program. Problems in learning and other cognitive areas (See Work Area, page 37; Learning Disabilities, page 75) probably accounted for this problem.

Because of this lack of understanding and compliance, staffings changed in form and content. Initial staffings attempted the achievement of a therapeutic goal of motivating the client by focusing on long term positive goals (such as acceptance by others or getting a job). However, many clients were misled or misperceived the intent of this approach and thus, were unable to deal with or relate to deficit areas (such as grooming, inappropriate behavior or poor basic work habits) which had to be corrected before attainment of the long range goals was possible.

So staffings in the later classes became more concrete and specific in terms of communicating to the client those deficit areas that needed work and what must be done to correct these problems.

CLIENT PROGRAM PARTICIPATION:

The following discussion will concern primarily the administrative and client process issues surrounding development and implementation of the client program. The Program Component sections of this report (pages 37 through 92) contain more detailed information regarding the philosophy, methodology, accomplishments and recommendations from each component section of the program.

The program was structured in phases which were self-limiting and were of 10-12 weeks duration. The phase concept was implemented in order to enable programming in particular areas for specific periods of time and in order to provide interim periods between phases of 2-4 weeks during which time the client would be able to return to his home environment to again confront the realities of that environment and test out new learning and new behaviors. The phase concept also enabled individual client programming to contain deadlines for goal attainment and choice points regarding decisions shaping future programming. Additionally, closed ended programming in various steps assisted in staff assessment of clients' ability to benefit from interventions at different levels, thus facilitating the prognostication of overall benefit.

Client goals for program participation were in four major areas:

1. Work related behaviors involved issues of dependability, independence, work habits, and work skills. The primary intervention in this area involved the Work Area which is described on pages 37 through 52.
2. Adaptive skills or acceptance skills were considered to be those critical interpersonal and psychological concerns relative to effective interpersonal functioning and self-acceptance.
3. Motivation and attitude- behaviors and qualities involved in this area were considered to be critical to clients' ability to benefit from Epi-Lab programming, and eventually to enter a vocational program.
4. Medical management involved issues such as medication compliance, maintenance of normal lifestyle, maintaining proper diet, etc.

All four program components were addressed in six major areas of program content. These areas will be briefly addressed here. A more detailed description is found in Chapter IV.

1. The Work Area was the primary vehicle for work-related behavioral evaluation and interventions. The majority of the clients' daily activities involved performing work-related tasks in the Work Area under the supervision of the Work Area Supervisor. The Work Area afforded the opportunity to observe not only work and interpersonal behaviors, but also seizure activity, medication side effects, etc.
2. Group Process was the primary vehicle by which to directly impact upon psychosocial issues. Groups were conducted by the psychologist and psychiatrist on Wednesday evenings with full-time staff conducting groups on Monday and Friday mornings. Groups provided individual clients with a structured opportunity to interact with other persons with seizure disorders, thus making possible not only a sharing of knowledge, but also the finding of solutions to common problems. Adaptive and interpersonal skill development was stressed, as was fostering the client's ability to focus upon positive aspects of himself, rather than concentrating on negative aspects such as seizures.
3. Recreation programming was provided on a regular basis three hours per week by the Center Recreation staff. Overall goals of the recreation activities were to extend the self, develop self-confidence and provide an opportunity for release of stress through physical

exertion. Recreation activities were also directed toward the goals of developing interpersonal skills, socialization skills, and fostering interpersonal competence. The acquisition of specific leisure time skills was also viewed as beneficial.

4. Some individual counseling was conducted for unique and individualized problems. Individual counseling also complemented groups by teaching students how to benefit from or use groups for personal problems, but group counseling and therapy were the primary modalities utilized in the counseling process. Issues involved in individual counseling were family problems, vocational problems, and personal issues not appropriate for group process.
5. Epilepsy class was developed in response to the observation that the clients themselves possessed many of the misconceptions and misunderstandings about their disorder that the general public held. Thus, classes were intended to address those medical, educational, attitudinal, vocational and societal issues involving epilepsy and its consequences which would enable the person to more appropriately and successfully advocate for himself and deal more effectively with persons in his home and work environment.
6. Medical treatment not only in neurology, but also in psychiatry and general medicine, was an important aspect of each client's program. Psychiatric intervention took the form of group therapy on a weekly basis. Neurological treatment was provided through the Center neurological consultant who examined each client and provided follow-up anti-convulsant management on a regular basis. Additionally, considerable effort was expended by the nurses and physicians in the Center Medical Clinic, providing support, as well as formal treatment for clients experiencing a variety of legitimate and manipulative medical problems.
7. Occupational Therapy - The Center Occupational Therapy Department worked with Epi-Lab clients on a referral basis from the Work Area Supervisor. The purpose of occupational therapy was to thoroughly evaluate and intervene upon those areas of perceptual-motor skill deficits, perceptual-learning problems, and independent living activities which involved impaired learning and cognitive abilities in clients with more severe brain damage.
8. Speech Pathology was also involved with some Epi-Lab clients in regard to communication and learning difficulties experienced by many of them.

Maintaining adequate communication between all disciplines

involved with the clients was a formidable task. Attempts were made to regularly schedule formal staffings, but these were difficult to maintain because of heavy time commitment schedules of all staff involved. Thus, the three full-time staff members of Epi-Lab informally discussed cases, compared notes, and exchanged information with all disciplines involved in the client program.

Documentation of program content for each client was considered to be critical to evaluation of client change and program effectiveness. Utilization of various forms such as the Rating Scale (See Appendix M), the Seizure Episode Report (See Appendix N), the Epilepsy Quiz (See Appendix O), the Medication Checklist (See Appendix O), etc., were attempts to routinely and objectively assess client characteristics. Additionally, most disciplines contributed written narrative reports to the client case file, which served as further documentation of client behavior and other concerns. In the area of psychometric testing, which was considered to be crucial because of the behavioral objectives of Epi-Lab, post-testing was accomplished at regular six month intervals on all clients who were accessible to the unit. On a bi-weekly basis the 16 Personality Factor Questionnaire was administered.

PROBLEMS:

Most problems which were experienced in various phases of program participation are discussed in the Client Program Components Section. However, several additional issues are appropriate to mention within the context of this discussion.

1. The need for increased family participation was recognized in many cases during the Epi-Lab program. Some efforts were made with a few clients to involve the family in the clients' program. However, due to many factors, primarily the geographical distance involved (clients came from all parts of West Virginia), effective family programming was not possible from this institutional setting.
2. Many of the initial goals in terms of number of clients served, rehabilitated, etc., were not reached because of the lengthy period of time required to thoroughly evaluate and program clients toward their goals. It is now estimated that approximately two years is required in a program of this kind to achieve significant results, and in some cases it may take that long to achieve a conclusive evaluation. This is understandable when it is considered that many of the problems addressed with the adult clients were the result of the developmental process and the problems were firmly ingrained as the result.

PRE-DISCHARGE PLANNING AND EVALUATION:

At the end of each cycle of Epi-Lab, assessment of each client's situation was made by the staff and by the client himself. The client's program toward essential goals was assessed and decisions in regard to program continuation, change of program emphasis toward other Center areas, or community services were made.

The Epi-Lab program (which consisted primarily of Work Area activities and Group therapy) was considered to be a pre-vocational personal adjustment program which enabled clients to improve in areas thought to be essential to success in job training or employment. Therefore, criteria were established in the client contract on an individual basis to serve as guidelines for any decisions involving movement of clients forward to vocational programming. The criteria were general for the whole population and not strictly adhered to because part of the purpose of the Project was to make an extensive and extended effort to define those areas which were critical to eventual vocational success.

Additionally, the program provided each client with every opportunity to allow time for change in critical areas. Thus, it was often difficult to predict the degree of change that clients would experience within a certain period of time, so definite choice points were not established for the entire group because of these individual differences.

The alternatives for clients beyond the pre-vocational stage of Epi-Lab included:

1. Vocational Evaluation - Referral to the Center's Vocational Evaluation unit for evaluation of specific job skills and identification of a specific vocational goal was made for those clients who showed vocational potential from a skill, motivation, and medical standpoint and who needed more information regarding those vocational skills before making a specific decision regarding their vocational future. When a client was identified as having vocational potential, vocational counseling was carried out by the Epi-Lab counselor (See Counseling section, page 57).
2. Job Training - Several clients entered directly into job training at the Rehabilitation Center and at a local college after a trial period in the training program. These clients were those that possessed adequate skills to pursue their chosen vocation and had attained satisfactory adjustment and insight to enable them to make a realistic vocational decision. The Epi-Lab staff provided vocational counseling, as well as some preliminary assessment such as the Wide Range Achievement Test, the Strong Vocational Interest Blank, the Ohio

Psychological, and the SAT prior to finalizing job training decisions.

3. Program Discontinuation - When clients' medical or psychological problems were too severe, if they could not adjust to Center life, if they were not sufficiently motivated, or if their behavior was violent or otherwise intolerable in the Rehabilitation Center and Epi-Lab system, decisions resulting in discontinuing their programs were made. On occasion these decisions were clear cut and some clients chose to terminate themselves from the program. However, most were difficult particularly in light of the program philosophy of providing each client with adequate time to demonstrate potential for improvement. However, some of the problems, such as cognitive difficulties, organic brain damage and related problems, perceptual motor problems, or learning disabilities, made it impossible for some clients to meet vocational selection criteria. As is discussed in the next section (pages 37 through 52), much effort was expended with these clients in "going the last mile" in attempting to find solutions to these difficult problems and thus identify some vocational potential. These efforts by the full-time staff, the Occupational Therapist, the Speech Pathologist, and the Learning Disabilities Consultant were particularly involved in this area. In spite of these efforts, some clients were discontinued because of program limitations or inability to find solutions to problems which were barriers to entry into vocational areas.

Many problems plagued the decision making process in this stage of pre-discharge planning and evaluation. Some of these are as follows:

1. The above paragraph points to the difficulty in establishing criteria for program discontinuation when client failure was involved. Every effort was made, often with considerable sacrifice and time (which could have been spent in working with additional clients) to exhaust all resources before giving up.
2. Another problem which effected many clients was an inadequate system of transition programming from the pre-vocational Epi-Lab program to vocational services. Several clients had derived maximum benefit from the Work Area and were thus not appropriate for continuation in that aspect of the program. However, they were not ready for job evaluation or training because of continued problems with seizure control, behavior, or lack of independence. This problem also effected the movement of clients out of the Work Area so new ones could enter. One example of this problem was resolved with a client who resided in the Charleston area. A community based program of independent living

and family intervention was devised in the home setting. This prevented her from stagnating in the Epi-Lab Work Area, while concentrating upon the critical issues for her which were self-assertion, independence, and freedom from parental dominance. This type of programming proved to be quite successful as a transition but was not possible for most clients because of the geographical location of their residence and because of limitation of staff coverage.

3. As the above statements indicate, it was often difficult to make decisions regarding program discontinuation. In all cases the program attempted to allow sufficient time for individual improvement. On several occasions, when staff believed that they had exhausted all resources available and that the client had derived maximum benefit, continued movement toward higher level goals took place and a greater degree of improvement or adjustment was realized. Thus, the staff attempted to be acutely aware of signs of eminent change. But it was learned from those clients who were in the program for two years that a change was a continual process and that for many of these persons programming toward improvement in behavioral areas could occupy a considerable period of time (from 1-5 years) and should be accomplished in a variety of community and institutional settings.

COMMUNITY RE-ENTRY - FOLLOW-UP:

The community re-entry and follow-up phases have been grouped together because the issues and problems involved are common to both. While this area is considered to be critical to the clients' ability to maintain improvements realized in the Rehabilitation Center setting, it is also an area that is difficult to control from this setting, especially for those persons from remote areas of this rural state. Therefore, many of the needs that must be met for these persons can be carried out by the client's community field counselor, family physician, or other social agencies such as the Department of Welfare or Community Mental Health Centers.

However, the Project was involved in assisting several clients who resided in the Charleston area with community re-entry and follow-up. Several were placed on jobs in the Charleston area and one attended a local college. For these clients, continuation of Group activities in the Project, individual counseling and attendance at the Neurological Clinic on an as needed basis provided follow-up in crucial areas. By keeping in close contact with these clients after exit from the Rehabilitation Center, the staff was able to monitor the clients' progress and provide assistance when difficulties arose.

The needs of the Epi-Lab clients continued to be similar after program exit as they were during program intervention. The needs that required attention included the following:

1. Medical follow-up - Seizure activity, medication blood levels, etc., which require monitoring and treatment, can be provided either through the family physician or through the clients' neurologist. These problems were easily resolved for clients who had access to medical treatment facilities or physicians' offices. However, some clients who resided in rural areas had difficulty accessing medical treatment and, as a result, had a higher chance of deterioration in medical condition.
2. Psychosocial intervention - Group therapy and counseling support proved crucial to maintenance of adjustment levels of clients in Epi-Lab. As they re-entered the community and again encountered family relationships, employers, and the general public, the likelihood for regression increased. The Epi-Lab program per se' was unable to meet the needs of these clients in outlying areas. However, Community Mental Health Centers and Agency field counselors should be in the position to help the client maintain improvements made during Epi-Lab programming.

Additionally, the families' understanding of and agreement with the program goals was considered to be crucial to the clients' ability to maintain levels of improvement. For example, if the Epi-Lab program enabled the client to be more independent in decision making and in travel, the family could destroy the progress made by continuing to impose those unnecessary restrictions that were placed on the client prior to his demonstrating in Epi-Lab that a higher level of functioning was possible.

3. Job Placement - For those clients with some vocational potential, job placement activities were almost solely the responsibility of Agency field counselors, or community based personnel. Some clients' success in obtaining and retaining employment is dependent upon many factors which the individual client cannot control. These include public attitudes, enlightenment of the field counselors regarding appropriate vocational decisions for the person with seizures, and an awareness by the placement officer of many clients' inability to perform in all aspects of many jobs. (See pages 52 and 53.)

Thus, in regard to job placement, personnel involved in this activity should be provided with appropriate training directed toward first overcoming their knowledge and attitude gaps in relation to epilepsy and second, acquiring the skills necessary to enlighten employers and make visible to them the skills and abilities of these people rather than focusing upon presence or absence of seizure activity.

The need for job modification must also be acknowledged in regard not only to safety factors, but also to the skill deficits which many of these persons possess.

The deficiencies in the area of community re-entry and follow-up are probably one of the main weaknesses of the Epi-Lab program. These aspects of the program were not developed sufficiently because of the statewide scope of the program, as well as the fact that only three clients who successfully completed the program were in need of these services. If the program is continued, these crucial areas should be scrutinized for it is believed that the clients' ability to maintain improvements and continue positive change will depend upon the support systems that are available to him in the community. In this regard, Epi-Lab cannot perform the job alone, but must, as stated above, depend upon field staff and other social agencies.

CHAPTER IV

CLIENT PROGRAM COMPONENTS

INTRODUCTION:

The client program was composed of nine major components, some of which were utilized for all clients, and some of which were intended only for special problem evaluation and intervention. Some were uniquely structured aspects of programming such as the Work Area, Groups, or Epilepsy Classes, but others involved existing disciplines and Center departments which have definite and specific contributions to make in different problem areas.

Most program components are described in this section by the professional staff member(s) who were involved with the clients in each area. It is hoped that this approach will enable a more thorough and valid assessment of each area of programming. It is also anticipated that the value of each profession's involvement in Epi-Lab will be most effectively communicated by the staff member(s) in that profession.

WORK-OBSERVATION AREA - Ethel B. Davidson, MSW

Historically, many persons with epilepsy have been unsuccessful in locating, gaining, and retaining employment in the competitive labor market, or have otherwise had negative vocational experiences directly or indirectly related to their seizure disorder. In designing Epi-Lab, the need to intensively evaluate the factors causing employment problems was recognized, so the Work Area was established as the essential component of the multidisciplinary Epilepsy Laboratory. The Work Area was constructed around the premise discussed in the literature (Rodin, 1968) and by professional experience (Shepherd & Gutknecht, 1966) which established that poor vocational success in this population was partially a result of psychosocial (behavioral) and cognitive deficits rather than seizure control. (Rodin, 1968) A controlled setting was thought to be essential to Epi-Lab if the behavioral and cognitive factors were to be thoroughly and accurately assessed; particularly if the impact of various interventions was to be understood.

The unit had three primary goals. First, this controlled, self-contained quasi-work setting was directed toward the monitoring and recording of behavior in order to determine the effect of epilepsy on the daily functioning of individual clients in a work setting. All disability related factors were considered, including behavior, nature and frequency of seizures, medication side effects, adjustment in activities of daily living, and interpersonal and coping skills. The observational data was recorded, not only as part of the total evaluation of the individual which was used in determining realistic life goals, but also for the broader purpose of gaining knowledge about the

impact of epilepsy upon this population in general, especially in regard to employment issues. This data collection was essential to the communication of vocational problems of the uncontrolled epileptic to those persons in the public and private sector, the helping professions in general, and particularly in Vocational Rehabilitation who could utilize any results of Epi-Lab in working toward the total rehabilitation of the person with epilepsy.

The Work Area provided the client a place to test out new behaviors which were learned in group therapy which was the primary client change agent. Students had a chance to test and practice newly learned alternative behaviors in the Work Area. There, through recorded observation, ratings, primarily, they gained feedback which was instrumental in modifying any maladaptive behavior that could be a barrier to vocational success.

The second goal of the Work Area was to evaluate the vocational strengths and weaknesses of each client and define specific interventions which might help to correct the weaknesses. The evaluation consisted primarily of two parts; one, the use of a variety of tasks ranging in degrees of complexity to determine types of skill strengths or weaknesses, and two, observation of pre-determined vocationally significant behavioral factors. Based on the observed strengths and weaknesses, specific interventions were designed with the objective of alleviating or compensating for the weaknesses, while at the same time strengthening or enhancing the positive traits and skills.

The process of evaluating and intervening could not be totally accomplished in the Work Area alone, so referrals to other departments became necessary. So, the third purpose of the Work Area became the screening of clients for problems which demanded the expertise of other professions and other departments. Often to merely define or label an observed problem required referrals to Speech Pathology, Occupational Therapy, or Behavioral Medicine. Sometimes the Work Area became a holding area with clients remaining in the unit for indefinite periods until the feasibility of other rehabilitation services could be decided.

NOT A WORKSHOP:

Physically, the Work Area was composed of one room, 1166 square feet, and storage space (See Appendix A). It accommodated numerous work stations, varied machinery and materials. (Specific work tasks are discussed in Appendix Q.) Its capacity was a maximum of 10 students at any one time and supervision was provided by the Work Area Supervisor with the assistance of the Secretary/Case-Aide.

The area was established on the workshop model, in that various subcontracted and direct contracted tasks were used as assessment tools. The need to fulfill these contracts was the

production goal, however, production was not made a major emphasis. Good work habits, quality performance and conformity to rules of the unit was emphasized. Several unique departures from the traditional workshop model include:

1. The clientele of the Work Area was a controlled group, in that each student, by definition, had to have uncontrolled seizures, had to have average intelligence, and had to be at least 18 years old. (See page 19 for details of selection criteria.) In addition, any secondary disability was not to be more disabling than the primary disability of epilepsy. Thus, the clients were a fairly homogeneous group compared with the typical heterogeneous disability groups found in most workshops.
2. The Work Area never had more than 10 students at any one time. This allowed the staff more time for more individualized programming and supervision. Each student had definite goals and needed help in various areas. With a full-time Work Area Supervisor and an assisting case-aide, interventions could be implemented on a more timely basis, progress monitored, and feedback given.
3. Most interestingly, the role of the Work Area Supervisor was a rather unique one, in that the staff member filling that role was a master's degree level social worker. Therefore, in addition to the production oriented supervision role typical of the traditional foreman, this staff member also lent expertise to the job in the areas of human behavior, interpersonal relations and social, as well as work adjustment. This enabled all evaluations of students for vocationally significant factors to be more broadly based. The professional knowledge acquired through social work training enhanced the variety and pertinence of intervention strategies necessary to deal effectively with the problems encountered in this uncontrolled seizure population.
4. Quite different than in the usual workshop, the purpose was not just work adjustment. In the Work Area, the objective was broadly based behavior change in interpersonal, intrapersonal, cognitive and other areas which aided in the determination of and preparation for readiness to pursue a realistic personal or vocational goal. Efforts were initiated by a contract (See Appendix L) with the Work Area student in which he agreed to work on areas of need. This signed contract gave the student a visible reminder of his commitment to established goals and a statement of staff commitment to him. It also told the student how his progress would be assessed and a target date for progression to the next level.
5. Finally, the Work Area departed from the traditional

workshop model not only by de-emphasizing production, but by not monetarily rewarding clients. The idea, besides management convenience, was to develop client reliance on internal motivators rather than material reward for personal accomplishments. Even more importantly, not paying clients was seen as a possible means of fostering identification with the Project - reward through pride in group achievement.

TRAINING OF STAFF:

Uncontrolled epilepsy being an enigma and behavior observation and skill definition being less than a concrete science, the two Work Area supervisory staff needed more training than their academic backgrounds or previous experience had afforded them. This training came in many forms.

1. The Work Area Supervisor and Secretary/Case-Aide spent many hours in other Center departments learning how other units evaluated skills and monitored and recorded behavior. A great deal of time was spent in the Center's Sheltered Workshop learning not only evaluative and observational techniques, but also actual jobs which would later be subcontracted from that workshop. These persons did the same things in the Arts and Crafts section of the Recreation Department. The Work Area Supervisor also spent a period of time in the Vocational Evaluation unit and the Pre-Vocational unit.
2. A second means of training came through out-of-state trips to other agencies and facilities working with the epileptic, the brain injured, and the multiply handicapped. Both the Work Area Supervisor and Case-Aide went to Epi-Hab, Inc., in Evansville, Indiana. This is an industrial plant which hires only persons with epilepsy to do contract work. The Work Area Supervisor went to the Woodrow Wilson Rehabilitation Center in Fishersville, Virginia to study their project for the chronically brain injured. As would be expected since both groups have deficits of varying degrees caused by brain injury, there were many similarities in problems and barriers to client progress and gaps in programming. Much information was gained both in terms of their approach to behavior change, recording instruments, vocational intervention strategies, and assessment techniques. Also, the Work Area Supervisor visited the Jewish Vocational Center in Cincinnati, Ohio to study their Learning Capacities Program. This program evaluated handicapped clients and designed interventions and job modifications to improve chances of vocational success.
3. One of the greatest learning experiences involved the process of developing a usable rating form (See

Appendix M). Many rating instruments were obtained and studied. The full-time staff of Epi-Lab then began designing a form that would include those work behaviors thought to be significant to vocational success, as well as those interpersonal skills and medical factors important to the well adjusted individual. The form had to be usable by the full-time Epi-Lab staff and all departments, especially Recreation, involved with Project clients. The evolutionary process took a hundred plus hours, months of trial and error, and went from a blank form with a title and four broad headings to the five category itemized form (See Appendix M). Through the form development process, much learning was accomplished in the areas of monitoring and recording behavior, being objective, collecting the essential information, defining the rating criteria, considering the rater as a variable, and so forth.

4. The greatest learning experience was practice. Working with real clients with varied problems and goals and interacting and coordinating efforts with consultant and Center departmental staff improved staff knowledge, Work Area and instrumental design and staff resourcefulness. Strengths and weaknesses became apparent and modifications were called for and made.

PROCESS:

Students entering the Work Area at the beginning of each cycle (See page 23, Entry Processing) were given an orientation. This orientation initially was random information presented verbally with the only exception being written rules posted above the time clock. Later, this orientation process evolved into a highly structured, oral presentation supplemented by handout materials. The handouts, which were thoroughly explained, included information about the purpose of the Work Area and the purpose of the clients' presence in the unit. It became apparent that this information, given in written form that could be referred to later, was essential because even though clients agreed to participate in the Epi-Lab Project, many continued to grapple with their purpose for being in the program beyond their nebulous idea of attaining seizure control. The orientation also gave the client information about the learning opportunities available, the rules and expectations, and the team approach practiced in the Work Area. The idea was to clearly delineate the students' responsibilities to and for himself and others, plus point out his reasonable expectations of the supervisory staff in the area.

The Work Area was designed to allow for individualization in client programming. Each student was given instruction on each machine and activity in the Work Area and each student was given the opportunity to practice and demonstrate his proficiency. This skill assessment, along with the ratings and possible consultant input, was the basis for determining specific individual needs and intervention modalities.

This individualized programming went a step further. The process of contracting, previously discussed (See page 24) enabled clients to participate in goal identification in a formal staffing (See Entry Processing, page 23). The problem areas, with the corresponding interventions, were written in the contract which the student signed. Since he received a copy, he was supposedly aware of his vocational deficits and agreed to work on a number of his difficulties.

WORK AREA AS EVALUATION UNIT:

Probably the most important segment of the Work Area was the evaluation. By observation and subsequent weekly ratings, each student was evaluated in the following broad categories: Dependability, Independence, Acceptance Skills, and Motivation and Attitude (See Appendix M). These contained a large number of factors felt to be necessary or desirable for successful vocational outcome. In addition, the evaluation process incorporated information obtained from referral sources such as Speech Pathology, Occupational Therapy, Behavioral Medicine, and so forth. These sources were frequently used to clarify obscure observations which seemed to indicate skill inadequacies or vocational barriers experienced by some clients. On occasion, observations were supplemented by the use of video cameras to record behavior or tape recorders into which clients could talk while working to give a better idea of organizational reasoning and problem solving ability and to provide feedback to clients, hopefully improving insight into a specific problem area.

In addition, this structured work environment enabled intensive evaluation of the vocational impact of the clients' seizure disorder. Epi-Lab staff had the opportunity to observe first-hand any seizures occurring during the work day and note significant information such as time away from the job required for recuperation; need for professional medical attention; any diminution in performance following a return to the job, and any incidental costs such as breakage resulting from seizure activity. In turn, these observations provided valuable information to the neurologist in his attempt at medical management of these uncontrolled patients.

WORK AREA AS INTERVENTION SITE:

Once specific problem areas were determined, the staff worked with each student on a contractual, goal-oriented basis in an attempt to remediate or circumvent vocationally significant problems. This often meant attempting to modify behaviors, change basic work habits, upgrade academic skill levels, teach techniques to circumvent memory deficits or motor skill difficulties, and so forth. Sometimes this involved facing the reality that there were other areas of need beyond the realm of feasibility during this Project. Interventions were individualized, therefore, such factors as student insight, acceptance, readiness, and capabilities had to be considered.

Recognizing the needs became easier than meeting the needs.

Initially, interventions were unstructured, untimed, trial and error attempts at remediation of unacceptable behavior and inadequate skill performance. These efforts, or some unknown coincidental factors, worked for some students with good cognitive ability, a high degree of self-motivation, good vocational skills, and little or no organic deficits. However, those students who were later identified as having severe learning difficulties did not appear to benefit from these initial efforts. Epi-Lab staff became aware that they lacked the more sophisticated expertise to deal effectively with the deficits of this segment of the population.

Other Rehabilitation Center departments such as Occupational Therapy and Speech Pathology were consulted but all had little knowledge available to deal with the adult learning disabled. Epi-Lab's psychological and psychiatric consultants also investigated the problem but found their disciplines inadequate to effectively intervene. The problem was this; if the large number of Epi-Lab clients with learning disabilities were to be vocationally successful, an effective intervention was necessary to enable them to learn various kinds of new information. This need was the impetus for later hiring an educational consultant. (See pages 75 through 86.)

A number of minor interventions borrowed from the behavioral modification model, such as "time out," rewards, and so forth were tried. Some worked and some did not. The major and most detrimental behavior problems experienced in the Work Area were not amenable to these attempts. However, two interventions deserve note.

First, a number of sub-programs were designed. Some of these were individual reading comprehension studies, activities of daily living, self-charting to improve work rate; learning disability programming and strategies to circumvent memory difficulties. None of these were very successful. Failure was probably due to an attempt to exceed the time, expertise, or resources available.

A second intervention was contracting with the students to be "assistant Instructors" in the Work Area. The student was selected based on his or her personal needs and ability to benefit from such an experience in addition to his abilities to render a service. This experience allowed more introverted students, with potential, an opportunity to develop their interpersonal skills, to become more assertive, to impart and gain skill knowledge, and to become more confident and independent in a work situation.

CLIENT MOVEMENT BEYOND WORK AREA:

At the end of each cycle, it was necessary to decide whether client goals had been sufficiently met to allow progression to a more advanced level of rehabilitation programming. In terms of Work Area involvement, a decision had to be made as to whether or

not the client should return to the unit for another cycle for either further evaluation or continuation of some intervention to improve skills or behavioral adjustment. If another cycle was not needed, the next appropriate step toward a vocational goal had to be defined. This determination was made based on the ratings, successful achievement of the contracted goals for that current cycle, staff judgement, consultant judgement, and client interest, needs and abilities. The decision making culminated during the last two weeks of a cycle and was finalized in a staffing involving the client and the three full-time Epi-Lab staff members. If another cycle in the Work Area was needed, goals were contracted with the client; however, if not, then necessary referrals were planned for and initiated. Referrals in most cases were to Vocational Evaluation, job tryouts, or training.

TRANSITION MODEL: (See also pages 86 through 91)

Beginning in January 1979, the Epi-Lab Project design, including the design of the Work Area, changed. This work unit's mission became evaluation only and the name was changed to Observation Area. The unit was to have not more than five clients for a maximum period of 30 days for the purpose of providing the referral source with a thorough evaluation of the individual's vocational strengths and weaknesses. The unit still looked at those problems related to the clients' epilepsy that would act as barriers to vocational adjustment, and looked for vocational skills, behaviors, and the need for other Center based services. Therefore, the new Observation Area still served the secondary function of being a source of referral to other areas of service, but only during the 30 day evaluation period. Intervention was no longer the forte.

This new design had definite advantages. One, this evaluation was for a specific period so it did not linger on indeterminately to the psychological detriment of the client and expense of the Agency. If services were appropriate and available, referrals were forthcoming and if not, alternatives could be explored. Secondly, this evaluation was highly structured. Most information to the client was written, as was information transmitted inter-departmentally and intradepartmentally. All factors being observed were clearly delineated and methods of administration of tasks were consistent (See Appendix R, Work Checklist). The evaluation was more vocationally oriented rather than behaviorally oriented as before. Even use of the ratings was probably more objective, as staff skill in the use of this instrument had been heightened by months of practice.

The modified design had a basic flaw - limited time. Because of the accelerated evaluation, some of the attractive features of the old design could not be incorporated. With only 30 days participation, lengthy interventions were impossible. Therefore, the evaluation could not address client response to interventions. The new model did not allow a real reading of reaction to stress; this is unfortunate, as stress is a very common trigger of seizures.

The new design did not allow adequate time for many of the handicapping behavioral problems to surface either. These things limited the thoroughness of the Work Area, so increased reliance upon other disciplines (psychiatry, psychology, Occupational Therapy, Speech Pathology) was necessary to fill the gaps.

ADVANTAGES OF WORK AREA CONCEPT:

The Work Area concept is a rather interesting one. As a separate quasi-work setting, this unit offered a number of advantages for the uncontrolled epileptic. It was a tolerant environment in which a client could work through the anger and dependency so common to this rejected, discriminated against, restricted population. This area was also a place to work through the often increased seizure activity brought on by the stress of a new experience, increased taxation on physical stamina and the painful growth of personal change. One of the Work Area's chief advantages was its value as a place in which to test reality. Many clients had to learn some very serious truths about themselves. Generally, epileptic clients must learn that seizures are not always the reason for vocational failure; many must learn how their negative behaviors effect their co-workers and all must learn their true potential for a successful rehabilitation program.

One unique advantage of the Work Area was that it allowed for the evaluation of severely disabled multi-handicapped individuals that could not successfully complete the traditional Vocational Evaluation using a sophisticated normed system such as the J. E. V. S. Clients with the potential to successfully participate in Vocational Evaluation were referred for services, but those too severely limited to participate were spared this frustrating and failing experience. The Work Area evaluation, supplemented by referral information, enabled determination of those skills the client had and provided knowledge of elements of activities a severely limited client might do.

Work Area participation allowed for better first-hand knowledge of the total person. It is well known that successful vocational achievement involves much more than job skills. Dependability, independence, motivation and attitude, acceptance skills, and medical management are all important factors in the total adjustment of the uncontrolled epileptic client.

The other advantage of the Work Area was its emphasis on behavior change. Rarely does traditional workshop staff have weekly access to psychological and psychiatric consultants to obtain advice in guiding clients toward satisfactory adjustment. Consultant and full-time staff were supporting clients in their strivings for personal growth, increased confidence and self-esteem, heightened internal motivation, independence and reasoning in thought and action, social adaptability, personal responsibility for behavior and commitment. Though these issues were dealt with in individual and group counseling, these areas were also emphasized during daily participation in the Work Area and feedback

was given in these areas through Work Area ratings and staff and peer verbal feedback.

PROBLEMS:

The Work Area concept appeared to be excellent in design, however, implementation was less smooth than anticipated. One unforeseen aspect was the fact that the criteria used to select clients for the Project was not an accurate measure of client characteristics. The population was not entirely as had been anticipated and planned for, namely adult uncontrolled epileptics functioning intelligently and skillfully, and having no secondary disability greater than their epilepsy. Most individuals in the Project presented a quite different picture. Seizure activity became the least important and probably the least frequent of the behaviors being monitored in the unit; in fact, some clients were so well controlled that no seizures occurred throughout their months of stay in the Work Area (See Seizure Frequency Table 24 on page 98). Less than 20% of the clients served had more than one seizure in the work place throughout their stay in the unit, even when that stay encompassed more than one cycle. This client population did demonstrate disabilities more handicapping than their epilepsy; including learning dysfunction, psychiatric problems, and organic brain syndrom. Over half of Epi-Lab's clients had severely impaired skills. There was a marked incidence of motor and perceptual skill deficits and memory difficulties. One might question the indirect relationship of these difficulties to the epilepsy, yet these specific deficits in many cases made the establishment of a vocational goal almost impossible especially when compounded by severe learning problems.

At least 50% of the clients who participated in the Work Area had severe learning problems (See Learning Disabilities section, page 75). Suspicions were aroused when people with average intelligence were unable to perform on very routine tasks, such as stuffing envelopes without constant supervision. Further testing began to point toward learning disabilities. Some clues were a discrepancy between verbal and performance IQ scores; reading comprehension problems, language deficits, extremely low academic functioning (despite grade attainment), tested difficulty in shifting sets, memory problems, diminished rates of new learning, perseveration, difficulties in thought formation, and difficulties with problem solving strategies. Test data was corroborated by practical failures in functioning on Work Area activities. The magnitude and frequency of this problem of learning disabilities had not been anticipated or prepared for in the program planning stages of Epi-Lab. The selection criteria for intelligence was assumed to be a safeguard from this type of problem. It was not. These difficulties represent a most severe handicap to vocational attainment.

One example of this was a male Epi-Lab client with average intelligence, and a high school diploma. He had severe perceptual and motor skill deficits, severe learning difficulties. Some of his learning problems included difficulties using the written

mode (instruction following deficiencies), listening comprehension, and impaired problem solving ability. This man had less than successful performance in the Work Area; had no successful performance areas on the J. E. V. S. Work Sample Battery, and no feasible vocational training area was found for him at the Center. This young man never had an observed seizure while at the Rehabilitation Center; in fact, he had a history of only nocturnal seizures before coming to this facility. Seizure activity, indeed epilepsy, was not the most handicapping problem for this client; learning problems compounded by motor and perceptual skill deficits and impaired problem solving abilities were the major vocational liabilities.

If the severity of learning disabilities had been anticipated in the program planning stage, better preparation (including more intensive and specific staff training) would have been made. This preparation may have increased program effectiveness in this area.

Dependent behavior also proved to be a significant characteristic of many clients selected for Epi-Lab services. Some exhibited a limited ability to function at a level commensurate with their chronological age. These persons had difficulty making independent logical decisions and acting on those decisions in a responsible way. Therefore, constant staff supervision was needed. A large amount of time and resources had to be used to teach developmental types of basic skills such as how to tell when hair is clean, when to ask for help with one's work, how to be ready to leave on time at the end of the day, and so forth.

Violent behavior is sometimes associated with epilepsy. Epi-Lab staff had the opportunity to observe and document this behavior in a number of severe epileptic clients. This behavior was the most disruptive force to confront the Epi-Lab unit as a whole and the Work Area specifically. Whether occurring in the unit itself or in other parts of the Rehabilitation Center between Epi-Lab students with residuals carrying over into the Work Area, it had a profound effect on the area. During the time surrounding one of these incidents, the mood of the clients in the area was extremely tense resulting in a high degree of outward emotionalism and extreme fear for the safety of some students, especially females. Thus, all efforts to complete contracts and subcontracts were negatively effected. In the Work Area property damage occurred once and bodily injury occurred twice. Other violent behavior by Epi-Lab students outside the Work Area occurred thrice and resulted in bodily injury, property damage, and/or the removal of those clients from the Center. Explosive but non-physical anger was frequently directed toward the staff. Constant supervision was necessary to minimize the possibility of further violent outbreaks and injury to students. All attempts at intervention to change this behavior failed. Neither psychological, psychiatric, nor neurological consultant staff could offer satisfactory or effective answers to the problem. Discussion with other professional resource people seemed to indicate that little is known about the solutions to this very real problem.

The underlying philosophy of the total Epi-Lab Project's client service program was the idea of changing maladaptive behavior to improve the vocational prognosis with this population. Behavioral intervention was to be implemented by the full-time staff, especially in the Work Area under the guidance of the psychological and psychiatric consultants. Group therapy was to be the primary change agent and the Work Area was considered the practice ground where a student could try newly learned behavior and receive feedback. In theory this was good, but the philosophy lacked some of the structure and practicality needed to implement it in daily activities, especially when extremely maladaptive behavior outbreaks, such as violence, occurred.

It was very difficult to make behavior change take place in the Work Area especially when clients did not perceive rewards or penalties. Successful achievement in the Project and possible further vocational planning were offered as goals. Many clients with abstract reasoning difficulties, unrealistic goals, and various organic manifestations could not relate to these goals or relate to consequences of their negative behaviors. The only effective penalty was termination; for some this was easier and possibly preferred to change.

Another issue in the Work Area was motivation or the lack of motivation. As alluded to before, there was a definite lack of motivation on the part of a majority of participants in the Project. Many transferred their dependency to the Project and the Center, and strongly desired to remain at the Center for reasons of security not accomplishment. Possible explanations for this lack of involvement include:

1. Clients often questioned the reasons for not receiving money for their work. Efforts by staff to explain or foster intrinsic values and motives fell short for most clients were not able to replace their interest in monetary rewards with concepts such as "self-improvement," "becoming able to get along with others," and "improving work habits."
2. The lack of motivation was probably due to a combination of a lack of insight and unrealistic goals. Many Epi-Lab clients were unable to recognize many of their deficits and understand the significance of those deficits. For example, it was very difficult for some students to recognize motor skill deficits and realize the effect they had on their work rate and production. Not realizing this, many clients aspired above their potential and set unrealistic vocational goals. More routine activities which offered success were not acceptable. Goals contracted with the clients were often not clearly understood after an interval of time had passed and contracted goals often did not become a commitment even when understood and agreed upon.
3. Because many of this population had difficulties with

abstract reasoning, the idea of short and long-term goals which must be achieved by a graduated process did not penetrate. Often, the goal sought by clients was not within reasonable expectations of the Project.

4. It might be hypothesized that motivation comes from an expectation of possible success based on experience of past successes. All of the Epi-Lab clients had one past experience in common - failure. Many lacked the confidence that they would ever succeed again, especially vocationally. For most, getting a job was an obscure idea with no specifics. Therefore, the reasonable expectation of success probably had no success seeds from which motivation could grow.

Roles and relationships between staff and students were not clearly perceived by students, and this lessened the effectiveness of the Work Area Supervisor as a supervisor. From the beginning of Epi-Lab until the change in Project design, all Epi-Lab full-time staff had to attend the Group Therapy sessions conducted on Wednesday night by the psychological and psychiatric consultants. During these sessions, role distinctions were to cease and clients and staff were to relate just as people. It was supposed to be a time of caring. However, clients were unable to distinguish the difference between therapeutic caring and vocational or on the job caring, tempered by expectations, standards, responsibilities and necessary professional and personal distance. Clients became confused about what to expect from staff and angered when their expectations were not met. Supervision was almost impossible to enforce because of these unrealistic expectations by some clients.

The Work Area was housed less than ideally. The unit was composed of one room which was separated from the main building of the Rehabilitation Center. Confinement to this small area while working with intensely emotional issues created stress for both staff and students. Numerous personalities with varying levels of adjustment and control participating in activities for approximately five hours a day in the same room aggravated maladaptive behavior patterns, frustration levels, and had a draining effect on energy levels, emotional involvement, and individual productivity. These factors may have contributed to the explosive-violent incidents. This is different than for other students in programs at the Rehabilitation Center because they have more opportunities to relate to different staff, be in different areas, and associate with a more heterogeneous peer group. Epi-Lab students came to the unit at 8:30 each day, spent the entire day with one disability group, saw their counselor in the same building, had some classes and some group therapy with the same peers. Even structured recreational activities were scheduled as a class. The familiarity and the intense involvement in each others problems became overwhelming for many. Stated differently, the Work Area being the type of unit it was, did not permit the flexibility needed to deal with some of the behavior problems that were encountered. Maladaptive behavior, especially violence, could not be isolated so that it did not harm others. There was no

place where a student could go for emotional release and so forth. The recognition of this problem provided a major incentive for the design and implementation of the transition model (See pages 86 through 92).

Work Area intervention identified the need for a transitional program between the Work Area and Vocational Evaluation and training. As stated previously, the Work Area was a holding area for clients preparing for a vocational goal. Clients in Epi-Lab were evaluated, worked on adjustment, and received counseling and various therapies. However, if a client exhausted his ability to benefit from the Work Area and still was not ready for job tryouts, training, or placement, there was no ready alternative for that individual. Thus, that person stayed in the Work Area. This limited the number of new clients that could be brought in for services and placed an unnecessary drain on staff time, supplies, and other resources.

ACCOMPLISHMENTS:

The Work Area was a success. The idea and operation had some accomplishments. The whole idea of the Epilepsy Project was to learn some things about this historically misunderstood population that could be used by Vocational Rehabilitation and others to deliver better services to the person with epilepsy. Here are some of the vocationally significant things that were learned:

1. Evaluation - The unique design of the Work Area provided an opportunity to recognize some of the significant vocational weaknesses of this population. Seizures were a problem, but were not the most vocationally handicapping condition the epileptic client experienced in Epi-Lab. Observation and testing of these clients indicated that learning disabilities, motor and perceptual skill deficits, language deficits, interpersonal skill deficits, and behavior problems represented as great, or a greater barrier to success in vocational training or placement. Furthermore, one should not make assumptions of vocational potential based only on IQ, grade level attainment, age, past employment history, or other recorded information because unrecognized organic and behavioral problems that were common with this epileptic population may preclude the clients' performing according to past levels of achievement.

It is significant to note that a number of clients were discovered to have significant learning difficulties that were heretofore undiagnosed, even though they had been clients in the Rehabilitation system for many years. This stimulated some limited research into the problem which revealed it to be a marked problem at the Rehabilitation Center, but one to which no one yet has the answer, particularly in the adult age groups. This is significant because it points out the gap in the ability of the

Vocational Rehabilitation Agency to thoroughly evaluate or program effectively for these individuals. The learning impaired client, such as encountered in Epi-Lab, cannot successfully perform in the traditional evaluation (J.E.V.S. or similarly normed systems). However, the more flexible, individualized semi-structured approach used by Epi-Lab does offer some help in assessing the individual's learning capacity, tolerances, ability to perform elements of tasks, and so forth.

Of equal accomplishment is the development of the rating instrument that offered structure and objectivity in looking at the behavioral components of vocational potential and readiness. It focused on the significant issues, yet was flexible enough to allow for individualization in observations.

2. Work Adjustment - In this area, two innovative ideas were tried which prove to have merit. First, the use of a professional staff person in the traditional foreman's role was a particular deviation from the workshop model. In order to have a viable behavior change program, one must have a person implementing, monitoring, and evaluating behavior that is trained in behavior. The person doing work adjustment is dealing with a human being, not just the production item of the factory foreman. Modification of maladaptive behavior requires creative and thoughtful interventions to achieve a specific goal, requires skill in monitoring and recording behavior and requires a knowledge of human behavior and relationships. The person doing work adjustment needs expertise more than knowledge of a craft. Even given a prescription, one must know how to fill it.

To be an elastic, effective, learning environment, the work adjustment unit has to de-emphasize production. This is particularly true when the individual clients are handicapped not only by behavioral difficulties, but cognitive and physical ones as well. With an emphasis on production, many learning opportunities cannot be fully utilized because of the need to meet contract demands.

3. Job Placement - Experiences in the Epi-Lab Work Area provide a better understanding of why job placement has been difficult with the severely disabled epileptic client. To begin with, training opportunities including those at the West Virginia Rehabilitation Center were found to be limited for the severely handicapped epileptic client, especially those with multiple handicaps. Because of the nature of the disability, many training activities were considered to be too dangerous. But a greater problem was that most areas were too technically or academically advanced for Epi-Lab clients to successfully

participate. Most clients had skills for only very routine activities such as janitorial or housekeeping, though more advanced females could choose clerical training and advanced males small engine repair. Also, community resources were limited. Most non-competitive facilities, and/or Sheltered Workshops, are for the mentally retarded.

Two significant pieces of information were discovered about community placement opportunities. It is possible to find competitive employment for people who are still actively having seizures. As with any other client, whatever the disability, the task is to find the right job for the right client. With the epileptic it is essential that employment be in an accepting, less stressful environment, doing a non-hazardous activity for which the person is qualified. However, it is more difficult to find employment or even training opportunities for those persons with epilepsy who have socially unacceptable behavioral components such as screaming, incontinence, explosive hostility or other extreme behavior as a manifestation of their seizure activity. These persons will probably require a skilled, enthusiastic advocate to help them locate employment.

A final piece of information for consideration, is the fact that many of the severely disabled cannot do a total job, but can do elements of a job. Of course, every employer wants the person that can do everything, but in advocating for the severely limited, one must sell those skills which they do possess.

PSYCHOSOCIAL INTERVENTION

David A. Clayman, Ph.D

Increased evidence has been presented to support the idea of relationship between psychological/behavioral and physiological/biological factors in the etiology and treatment of various seizure disorders (Feldman and Paul, 1976; Williams, Spiegel and Mostofsky, 1978). Stress is a primary precipitating factor, as well as possibly behaviorally conditioned sequences involving seizure behavior, have been reported (Seifert and Lubar, 1975; Zlutnick, Mayville and Moffat, 1975; Feldman and Paul, 1976; Mostofsky and Balaschak, 1977). The greatest number of patients with seizures achieve adequate control using pharmacologic agents. This leaves 25 to 30% of seizure patients with only partial control and another 20% of patients with seizure activity that has been judged to be inadequate (Sands and Minter, 1977). In all of these cases it may be assumed that the seizure activity, as well as the impact of having epilepsy, interferes with successful social adjustment. The limitations and stigma attached to epilepsy becomes more severe as the chances for continued seizure activity increases. Family, social and vocational components of

one's life, often through ignorance, create an environment detrimental to the adaptation of the individual (Sands and Zalkind, 1975; Arangio, 1976; Caveness, Merritt, and Gallup, 1974).

Much of the literature presents epilepsy from a multi-professional perspective. Usually included are medical, psychological, social, economic and vocational factors. Use of a truly coordinated program that would include representatives from several professions should maximize the possibility that identified individuals will achieve more adequate seizure control and experience subsequent improvement in the quality of life. The design of the Epi-Lab program emphasized the psychological needs of patients with uncontrolled seizures yielding no one way to explain all of the interactions between the biologic condition and the behavioral readouts.

Among others, Feldman and Paul (1976) have indicated that any number of stress factors may increase the potential for occurrence of seizures in persons prone to such activity. Often, patients do not appear to have developed an adequate alternative response pattern to deal with increased life stresses. Thus, increasing the breadth of an individual's behavioral repertoire would be seen as a means of decreasing the probability of stress induced seizure activity. Patients who become more competent in handling stresses in their lives should reduce the degree to which anxiety may interact with biomedical variables that lead to seizure activity. Thus, if seizures had been a major reaction to stress, reduction of this behavior should be recorded.

When an individual continually experiences a seizure when under specific stress situations, this type of reaction may generalize to any stress event. The seizure may be the result of anticipated specific stresses and then may become a conditioned reaction under generalized stimulus situations. Reinforcement of this pattern may occur. Seizures may attract attention from others who would otherwise ignore the individual. Additionally, seizures may provide a means of avoiding stress or escaping from aversive situations. These patterns often are not recognized by the individual, the family, or even primary health care providers. Under these conditions it is difficult to educate patients and their families regarding the association between seizure activity and various behavioral variables. Such activity is necessary and often might require separation of the identified seizure patient from the home environment in order that they may develop an independent sense of themselves and the way in which they react to their environment.

The described conditions under which seizures occur have resulted in the assessment by care providers that seizures are not real. The contention in many of these cases is made that no documentation of seizures by EEG is available during most of these episodes, thus, the authenticity of the seizure is doubted (Williams, Spiegel, and Mostofsky, 1978). It is necessary to consider whether neurologists and other physicians treat actual

seizures or address themselves to the report by the patient and the family members of the subjective experience of seizures. This distinction is important. If a patient decreases the focus on seizures as a primary behavior, then a physician will be less likely to address this as a fundamental symptom. The patient's status, secondary to the use of anticonvulsant medications, will also be less likely to be compromised. Etiology may not be as critical as the degree to which patients focus upon their symptoms and report these to the primary care provider.

Finally, an undetermined percentage of patients continue to experience regulation problems because of compliance in fractions. When the payoff for continued seizures outweighs the benefits of control, patients may be prone to less than adequate adherence to medical regimens. The contention may be made that this failure to take medications as prescribed is due to ignorance on the part of the patient. Intervention with persons with uncontrolled seizures should address this and eliminate this possibility as a reason for non-compliance. Often, the failure of the patient to take medications is the result of the need to maintain seizure activity as a means of asserting control over an otherwise uncontrollable environment. Consistent with the contentions set forth by Dabbert and McLin (1978), Rodin (1976), and Lawall (1976), it appears that persons with seizures experience a significant degree of social and emotional upheaval. The exact nature of this has been left undefined (Hermann, 1977). Over a prolonged period of time, as seizures effect a person's life, patients might develop a poor adjustment pattern that effects their self-image and the manner in which others treat them. No single pattern has been reliably associated with persons with seizures. For those experiencing non-control, psychological variables appear to play as important a role as those biomedical factors that have appeared in the medical literature.

Any treatment program must then try to address the issue of measurement regarding psychological variables. Such an evaluation was undertaken in the Epi-Lab program where participants were exposed to a variety of psychological tests. Due to complications with computer services involved in assessing the data, these comments are to be considered superficial with a complete report being offered as a supplement to this program description.

The psychometric battery was administered to all clients within the first one to two weeks of their matriculation within the program. Included in this battery were the Weschler Adult Intelligence Scale, the Wide Range Achievement Test, the MMPI/CPI (Combined Form), the Tennessee Self-Concept Scale, the Bell Adjustment Inventory, the Mooney Problem Checklist (Adult Form), the 16 PF, and the I-E Scale.

Confirming previous results (Hermann, 1977), no consistent MMPI Profile was seen in the population at the time of program entry. There also does not appear to be an association between MMPI Profiles, the type of seizure that has been diagnosed, or the manifest behaviors on the parts of the clients. The degree to

which certain types or parts of profiles may be predictive of successful program participation are not available at this time. In assessing the I-E scores, no significant differences were seen between men and women nor between the groups of persons considered to have been successful at completing the program versus those that were seen as unsuccessful at the termination of the Project. Efforts were made to compare the first and last MMPI Profiles obtained on each client during their participation in the Epi-Lab program. Using those from the first 15 participants, four independent raters were asked to determine which of two randomly presented profiles (by subject) were "less pathologic." Inter-rater reliability was not computed, but all raters determined that seven clients showed decreased pathology, but between another four and seven showing an increase in pathology. The amount of time spent in the program and the outcomes of each of these participants were not included in this current analysis.

Similar ratings were computed on the CPI with most cases being seen as not different. The remainder appeared to show "better" CPI Profiles on the first administration which means that while decreases in levels of psychopathology were seen, those variables examined by the CPI showed a somewhat different trend. This discrepancy between the MMPI and CPI ratings leaves many unanswered questions.

Principal areas of concern revealed on the Mooney Problem Checklist were self-improvement ($\bar{X}=10.555$) and personality ($\bar{X}=18.52$). Interestingly, and in comparison, health concerns were minimal ($\bar{X}=7.0$). This contrast with the average health scores on the Bell Adjustment Inventory which appear to fall in the unsatisfactory range ($\bar{X}=10.45$). It is difficult to determine whether there are any sex-linked or other differences because further comparisons were not possible at the time of this report.

Additionally, many of the clients were administered the Halstead-Reitan Neuropsychological Battery. Evidence of neuropsychological involvement has been suggested by many authors who feel that individuals with epilepsy experience organic impairment that effects their adjustment (Dikmen, Matthews, and Harley, 1975; Lou, Brandt and Bruhn, 1977). The results of the neuropsychological testing will be assessed in a supplemental presentation of psychometric data. Further comments regarding the psychometrics are not possible given the status of the data analysis. A supplemental report will be necessary to deal with these aspects.

PSYCHOSOCIAL INTERVENTION:

Group Methodology - Pinckney McIlwain, M. D., Psychiatric Consultant

"From the inception of the idea for the Epi-Lab Project, it was strongly held by both the staff and consultants that a major

factor preventing many individuals with uncontrolled seizures from obtaining meaningful employment was behavioral. This has been previously documented in the literature by many authors. Since behavioral aberration was felt to be such a significant factor in the poor employability of this group of individuals, it was felt that some means must be developed to deal with this problem. As a result, the psychiatric and psychological consultants determined that some form of group intervention would be beneficial. This would allow for the continual evaluation and re-evaluation of such behavioral aberrancies as might be manifest while the individual was a participant in the Epilepsy Rehabilitation Project, as well as providing the staff and consultants with a common ground for discussion of improvement or lack thereof.

At the outset of the Project, an open-ended group format was elected which required the participation of all staff and clients directly served by the Epilepsy Project. The principals utilized in directing the group were derived from many sources, most notably Yallum's work, "The Theory and Practice of Group Psychotherapy." The concept of this form of therapeutic intervention was initially foreign to the Rehabilitation Center setting. Initial resistance was remarkably low, however.

The first group of clients who participated in the Epilepsy Project ultimately appeared to benefit from the group process more than subsequent clients. By utilizing this methodology, a significant attachment developed between staff, clients, and consultants, leading to the realization that a single goal was the aim of all participants. The group process thrived for a significant period of time during the Epilepsy Project. Towards the end of the Project, as turnover in the group increased and staff and consultant commitment to the Project began to decline, the group became less effective in shaping more socially acceptable behaviors. This change and response to the group was an experience common to both the psychological and psychiatric consultants.

The single group that was run by the psychological and psychiatric consultants was not the only group held during the week. Periodic groups were also managed by the staff of the Epilepsy Rehabilitation Project. An initial precept in formulating the groups and asking for staff participation was the hopeful development of group leadership skills among individuals who had never had such experience. It was felt that ultimately the development of these skills would facilitate successful vocational rehabilitation in settings other than Epi-Lab. As a result, in addition to attendance at the single group led by the consultants, the Project staff also held groups at several other times during the week. These groups appeared to function quite well during the earlier phases of the Project and ultimately evolved as an excellent method for teaching the Project clients about themselves. As with the group led by the consultants, interest in these secondary groups waned as the Project approached its end point."

All groups served to focus staff and client attention on behavioral issues such as reducing inappropriate behavior, improving interpersonal skills, developing adaptive skills, etc. Problems of lifestyle management surfaced as the clients' life experiences as residents of the Rehabilitation Center increased. These issues such as rejection by others, sheltering by parents, treatment by others during seizures, relating effectively with peers and supervisors, etc., provided realistic examples of real-life issues that all clients had to face if they were to live successfully in society.

It was believed that much of the improvement experienced by clients in various behavioral areas was due to the dynamics of the group process.

COUNSELING - David K. Steurer, CRC

The counseling function in Epi-Lab was carried out by various staff members in different settings within the Rehabilitation Center. Though counseling was a major role of the counselor/coordinator, this function was also a portion of the role of the case-aide, Work Area Supervisor, and the consultive staff. Clients tended to relate to various staff members on an individual basis, depending upon factors such as ease in establishing rapport, trust, etc.

Group counseling was the primary vehicle utilized in working toward goals in the area of psychosocial intervention. Individual counseling was discouraged except in situations which demanded individual attention and when issues of vocational exploration and other specific vocational issues were involved. Many of the counseling goals, especially those in psychosocial and educational areas, were accomplished in the entirety of Epi-Lab and the individual counseling served only to support and reinforce these others aspects of the program.

The counselor/coordinator served all clients in the Project as a Rehabilitation counselor. In this role he managed all cases in regard to the Rehabilitation process and coordinated programs outside of the Epi-Lab unit. He was responsible for maintaining communication with the clients' field counselor, providing periodic reports to the field counselor regarding client progress and arranging for follow-up services at the conclusion of the Epi-Lab program.

Vocational counseling was the major area which occupied individual counseling time. Many issues and problems that were involved in the vocational counseling process made it quite difficult to address critical issues involving their vocational future with the majority of clients. Some of the major problems were as follows:

1. Those clients who had limitations related to organic brain damage, communication deficits, learning problems, cognitive deficits, etc., had limited insight into their limitations, especially in areas of behavior and the impact that these limitations would have upon their eventual vocational future.
2. Many clients significantly over-aspired to vocational goals beyond their capabilities.
3. Many clients failed to realize the importance of facilitating positive attitudes of employers and co-workers.
4. Communication skill deficits (see Speech Pathologist section, page 74) in many clients made verbal counseling difficult and often impossible.
5. Many clients' tendency to persevere caused problems in facilitating positive movement toward specific goals through the counseling process.
6. Many clients found it quite difficult to invest trust and establish rapport with staff in a counseling role. This may have been due in part to the administrative functions of the counselor/coordinator which sometimes compromised his role as counselor. Also, perhaps because of the many rejections, frustrations and disappointments that the clients had experienced in relating to other people, their level of suspicion and mistrust was elevated and trust became a difficult issue in any new relationship. A frequent occurrence was for the clients to "test the staff" with opportunities to prove their caring before trust was invested. Also, role expectations were often unrealistic and thus, opportunities for disappointment when these expectations were not met were present. For example, it was common for some clients to expect the counselor to be available at a moment's notice to listen to minor complaints or problems. When this was not appropriate or possible, these clients often misinterpreted the situation and felt that the counselor did not "care about them."
7. It appeared that previous vocational experiences were often a hinderance to realistic vocational planning in the present. For example, if a client had held a job successfully in the past, the client may now be unwilling or unable to recognize diminished cognitive abilities, impaired performance skills, and other factors that would preclude his return to that previously held type of occupation.
8. Counseling was difficult because many of the clients did not have goals. If they stated any goals, they

were global, often unrealistic goals. Typical goals were jobs, independence, and "no more seizures." Goals were not specific or incremental.

Generally speaking, the individual counseling process was felt to be relatively ineffective compared to the Group, Work Area and Epilepsy Classes. The problems mentioned above combine to make it quite difficult to utilize the traditional counseling relationship as an effective change agent. As is discussed in the section on Group Process, peer influence and group pressure were viewed as much more powerful and significant in the lives of the clients than any individual staff member.

On the positive side, counseling relationships improved and effectiveness of counseling increased in those clients who became more successful in the program. It was observed that those clients who became more confident, better adjusted, and more highly motivated developed more trust and rapport with staff in a counseling role and were thus more accepting of staff intervention.

RECOMMENDATIONS:

Persons working in a counseling role with epileptic clients similar to this population should be acutely aware of the extreme suspicion and mistrust which these clients feel for "professional people in a helping role."

This points to an additional reason for the clients' reluctance to trust the staff in a counseling role which might have been due to their experiences of continuing to have seizures in spite of the "helping" efforts of other, primarily medical, professionals. Many high hopes for control and "cure" of their seizure disorder have been elevated and then dashed by recurrence of seizure activity. Also, many promises made by others in the helping role have proved to be untrue, such as a doctor telling a patient that some day he would grow out of his seizures, only to find that as the years passed, the seizures became worse or did not improve. Suspicion of others is also reinforced by being rejected by friends or family members in spite of their continued expressions to the effect that the seizures would make no difference in relationships.

All of these situations point out the reality of the psychological and behavioral problems that are major barriers to successful life adjustment. Unfortunately, these same problems seem to create additional barriers that make change more difficult by preventing helping efforts from penetrating.

One technique which assisted some clients in overcoming their inability to perceive deficit areas and utilize verbal communication effectively, was the video-tape equipment which was purchased by the Project. Client activity in the Work Area, in Group, and in class was taped on occasion and utilized in providing feedback to clients in regard to their interpersonal

skills, their work behavior and habits, and their appearance and personal grooming. On some occasions, when clients had the opportunity to view themselves via television as other people saw them, a greater impact was made and sudden movement toward change resulted. This tool should be more widely utilized in programs of this type.

EPILEPSY CLASSES

Even though Epi-Lab was a program for people with epilepsy, the subject of seizure frequency and issues and problems surrounding the disorder were not topics of concern in work activities or group activities a majority of the time. In fact, programming efforts discouraged the clients from becoming preoccupied with discussing their seizures, their medications, their frustrations and rejections, etc., except during the initial phases when catharsis was necessary. Rather, it was the basic philosophy of the program that in order for behavioral improvement to occur, a focus away from seizures was necessary.

However, it was observed during the initial months of Epi-Lab that students possessed many of the negative, defeating attitudes that were held by others in society and that often they did not have sufficient understanding of their disorder to enable them to discuss it intelligently with others or advocate successfully for themselves in important situations such as job interviews. Therefore, a class was designed for the purpose of providing a basic understanding of epilepsy and its consequences. This understanding was thought to be a prerequisite to insight and improved self-image which were necessary to the attainment of the primary program goal of learning to live with epilepsy.

The following outlines represent the primary goals and content areas of the two classes which were designed to meet these needs:

EPILEPSY CLASS, COURSE I

AIMS AND GOALS OF INSTRUCTION UNITS ON EPILEPSY

- A. To give the students in Epi-Lab factual information about their disability so they will:
 1. Understand the temporary nature of an epileptic seizure and its causes,
 2. Be able to properly handle a seizure and teach others to be more comfortable with them and their handicap,
 3. Better understand their responsibility to comply with treatment efforts, and
 4. Be able to advocate for themselves and effectively dispel some of the misconceptions associated with epilepsy in relating to other persons and society in general.

B. To examine public and personal attitudes toward the epileptic person by looking at:

1. The influence of American values on societal views of the epileptic person,
2. The psychosocial implications of epileptic seizures,
3. Personal reactions to past experiences, situations, and interpersonal interactions,
4. Responsibility for personal behavior, and
5. The influence of attitudes on the availability and use of opportunities.

CONTENTS

CLASS I	Orientation	
CLASS II	Evaluation	
CLASS III	First Aid	
CLASS IV	History of Epilepsy	
CLASS V	Attitudes and Society	
CLASS VI	Attitudes and Feelings About Epilepsy	
CLASS VII	Psychosocial Aspects or Typical Problems	
CLASS VIII	Seizures and the Brain	
CLASS IX	Epilepsy: Its Causes and Treatment	
CLASS X	Commonly Held Misconceptions	
CLASS XI	Re-evaluation	(See also Appendix S)

PARTICIPANTS

All clients during their first cycle.

EPILEPSY CLASS, COURSE II

AIMS AND GOALS FOR CLIENTS

1. To become able to present self to achieve more comfortable functioning in personal, vocational and recreational settings (assertiveness, appearance, posture, etc.).
2. To learn how and when to appropriately discuss epilepsy and to be able to tell others what to do if seizure occurs.
3. To foster feelings of responsibility for self and others with epilepsy (Advocacy) - EFA orientation.
4. To become proficient in all employment related situations: applications, interviews, co-workers, supervisors, seizure on job, etc.
5. To apply knowledge of self and seizures to advocate for self in order to achieve positive results.

6. To improve ability to achieve independence in community living.
7. To relate effectively with authority figures (employers, landlords, etc.).

CONTENT

1. Films on epilepsy, employment, advocacy
2. Role playing of situations in above categories
3. Self-help - definition and implementation
4. Peer feedback, videoc-tape feedback, and discussion

PARTICIPANTS

Those clients who demonstrate vocational potential and who will enter training or employment in the near future.

* * * * *

The Epilepsy Class - Course I was fully implemented and utilized in several cycles of Epi-Lab. However, Epilepsy Class - Course II was attempted on several occasions but due to client attrition and other circumstances, it was never fully implemented as part of the program. However, the needs of the clients in these areas toward which the class was directed are considered to be significant and real.

In order to measure the effectiveness of the class, an Epilepsy Quiz (See Appendix O) was devised, utilizing items taken from the Epilepsy Quiz published in Epilepsy on the Way to Work, by the Epilepsy Foundation of American, as well as other items devised by the staff. A breakdown of client scores on this quiz is included in Appendix T, but this instrument did not prove to be related to client outcome or results of an individual client's programming.

The Epilepsy Class was observed to be of benefit to many students for it provided them opportunities to ask questions relative to their disorder and correct misunderstandings which they previously had possessed. However, their resistance to change, as pointed out in the Counseling Section, was evident in the classes and often presentation of new or enlightening information met with resistance. This was especially true when the information presented encouraged a change in client attitude or behavior. The tendency of most clients was to continue to "crusade" for society to change and cease the mistreatment "that it inflicted upon them." In responding to the student questionnaire (Appendix U), only 6 (37%) expressed that the classes was one of the services that helped them the most. This would tend to support this observation.

A good example of this phenomenon was the clients' reluctance to believe that use of a tongue blade or other object to prevent

swallowing of the tongue during a seizure was no longer recommended or necessary. The interpretation by some clients was that not using a tongue blade represented inadequate and improper treatment.

It was observed that the clients who benefited most from the program were those that were highly motivated for self-improvement and who possessed those intellectual and cognitive skills necessary for self-improvement. Those clients who had cognitive and learning difficulties and communication problems experienced minimal benefit, in the observation of the staff, from this type of programming.

It is recommended that future work with epileptic clients include epilepsy class programming of the type provided in Epi-Lab for those that are of average intelligence and are otherwise capable of insight and understanding of the subject matter.

Clients who are less able should also be exposed to this information, but it should be individually programmed in a counseling relationship where individual problems can be more closely monitored and understanding can be assured.

Client motivation is also a significant factor in determining the effectiveness of providing information such as was addressed in the classes. Many clients do not want to discuss epilepsy or be reminded that they have it, even though they are experiencing frequent seizures. Efforts to enhance self-understanding and self-acceptance through education are not successful for this type of person.

Student Chapter - Epilepsy Foundation of America:

As an extension of the epilepsy class and of Epi-Lab, an effort was made to offer the class curriculum of Epi-Lab to other students with epilepsy at the Rehabilitation Center. Considerable effort was expended in attempting to organize a student chapter of the Epilepsy Foundation of America for the purpose of involving all students with epilepsy in an effort to:

1. stimulate interest throughout the Center about epilepsy and what should be done if a seizure occurs;
2. help people with seizures learn to speak for themselves and become able to talk about their seizures to people who should be aware of their condition;
3. educate people with seizures and interested persons about the facts of epilepsy;
4. reach out to others, work together and show others that people with epilepsy are capable of living normal lives;
5. make people more aware of epilepsy and attempt to eliminate negative attitudes such as rejection, embarrassment, anger and fear;

6. provide encouragement to students with seizures who are afraid to be open about their condition;
7. stimulate the person with seizures to prove to himself and others that he can become a responsible and successful person, and
8. involve students with seizures in a group effort to help themselves and others, thus producing greater self-acceptance of their condition.

In spite of efforts to educate the Rehabilitation Center clients, including those students participating in Epi-Lab, through displays, posters, articles in student newspapers, etc., of the benefits of this type of organization, it proved to be a failure. It is believed that the basic reason for the failure of this effort was the fact that very few students with epilepsy were interested in self-advocacy and were unable to acknowledge their need for assistance in self-improvement and increased understanding of their disorder.

It is believed that if some requirement was made of these students to attend the chapter meetings and if some support from the Center staff had been given regarding the importance of this type of opportunity to their eventual adjustment and job potential, that the results may have been different.

In summary, educational efforts of people with epilepsy regarding issues and information concerning their disorder appear useful and important in the design phases, but through the experience of Epi-Lab are quite difficult to implement due to problems in client motivation and ability.

RECREATION

The Center Recreation Department was a part of the Epi-Lab program from its initiation. Recreation staff were involved in the initial staff training (See pages 9 through 11) prior to program initiation, as well as in the planning of the total program. Consistent participation in staffings insured good communication of critical information on clients' after hours behavior and interpersonal relationships.

The original premise for including Recreation in Epi-Lab involved the knowledge that many persons with epilepsy were unnecessarily restricted by parents or other caretakers or had unnecessarily restricted themselves from participating in recreational or leisure time activities, especially those involving the more physical of activities. This assumption proved to be true in many cases and the result was observed to be a significant limiting of overall life functioning in non-vocational areas.

All clients served in Epi-Lab were interviewed by the Recreation staff in regard to issues specifically related to leisure time utilization and need for formal programming. During the

first five classes prior to the initiation of the transition model (See pages 86 through 91), the clients were scheduled 3 hours per week during the work hours in addition to evening programming. These 3 hours involved 1 hour in creative arts, 1 hour in specific skill activities, and 1 hour in music and drama.

The following information was contributed to this report by two of the staff members in the Center Recreation Department. Their impressions of both their work with the clients and their relationship to the Epi-Lab unit are significant and reinforce the previously discussed value of the multi-disciplinary approach to this population.

Final Evaluation of Developmental Recreation Element's Role in the Epi-Lab Project - Ann Lacy, Recreation Director:

Recreation was regarded as a vital portion of the comprehensive program for each individual. Including our department in orientation of epilepsy, weekly staffings, and student evaluations provided us with vital information necessary for establishment of appropriate Prescribed Leisure programs. Information such as an individual's progress, program goals, targeted behaviors (interventions), and psychological testing were available for our use. Recreation was considered as a portion of the treatment team, thus allowing treatment of the total individual. Another necessary factor was the degree in which Epi-Lab staff supported our program; communication among departments was a plus.

In summary, our goals and objectives within the Developmental Unit were as follows:

Goals: To treat the whole person
To develop independent leisure functioning.

Objectives: To teach leisure skills.
To encourage appropriate social interaction.
To enhance an understanding of leisure values.
To improve self-concept.
To promote physical fitness.
To provide acceptable outlets for expression of emotions.
To increase tolerance for stress.
To provide a better understanding of purposeful body movement.

Behaviors involving social aspects, attitudes, and movement were well ingrained by the time they came to the Center. We were able to assess and identify individual's needs, most of which necessitated long-term treatment. The feasibility of this type of treatment was very questionable in our facility due to the length of time required to increase the low levels of functioning. Developmentally, it is difficult to effect a change in many behavior and motor patterns.

The individual prescribed leisure programming was successful

once the "life-time barriers" were broken down with each student. The greatest amount of time was spent in "Leisure Counseling" sessions in obtaining the individual's recognition and understanding of his/her needs and the functions that recreation could provide to meet his/her needs. If this understanding was established, participation from the individual in prescribed activities presented little, if any, difficulties. Our greatest headache was developing understanding of leisure functioning and motivation; not due to their seizures, but due to their deeply ingrained behaviors, particularly of the emotional domain. Seizures seemed to play a very small part in the motivation and behaviors of these individuals. Personally, I felt that several of the individuals were not functioning adequately in the affective domain to successfully cope in our setting. Some individuals were accepted for services prematurely.

An individual with epilepsy should be encouraged to participate in activities in order to enrich and improve the quality of his/her lifestyle. Careful selection and appropriate development of leisure time pursuits can serve as a valuable contribution. "Normalizing" individuals' lifestyles and freeing him/her from unnecessary barriers or restrictions was accomplished with only a minority of Epi-Lab students. For those individuals who were flexible and demonstrated desire, the program was appropriate and the result was leisure independence.

Christie Mann, Recreation Director:

Seizures seemed to be a small part of the problems encountered with this group. Many of their social behaviors, attitudes, and movement behaviors have been well ingrained by the time they reached adulthood. Developmentally, it is very difficult to effect a change in many of their motor patterns.

Success of individual recreation programs seemed to be dependent on how well the student recognized he had a need to meet and that recreation could help him meet that need. The Epi-Lab staff was very supportive. Programs were most successful when the student played a large part in the planning.

Communication was a plus. Beginning with the orientation of staff members to the program before the clients arrived and continuing through weekly and bi-weekly staffings, Recreation was well informed of clients' progress, program goals, interventions. Psychological testing and other information was available. The Rating Forms used by the Epi-Lab staff were adaptable by Recreation for Epi-Lab needs.

Much has already been written on activities which are appropriate for people with seizure disorders and will not be dealt with in detail here. High risk sports, such as swimming, diving, horse-back riding and trampoline would be inadvisable except in extremely well controlled clients at the discretion of the physician, with appropriate safety equipment and alert supervision. The person

with epilepsy should be encouraged to participate in activities which will enrich and improve the quality of his life. This is where the careful selection and development of leisure time pursuits can make a valuable contribution.

MEDICAL:

This Project for severe epileptics made special demands upon the Medical Service element at the West Virginia Rehabilitation Center even though medical treatment of these individuals was not a primary program area. The program impacted upon many areas, including medical laboratory utilization, nursing care, general medical practice, neurological evaluation and treatment, and psychiatric evaluation and treatment. To examine, in depth, the medical issues relating to epilepsy is not within the scope of this report, but it is important to describe the roles of the various medical specialities as they functioned in the Center setting in the treatment of the Epi-Lab client, to relate the problems encountered in providing necessary medical care, and discuss the accomplishments in improving overall medical treatment to all epileptic clients at the Rehabilitation Center which resulted from the Epi-Lab program.

The three types of physicians that treated the clients from Epi-Lab were the clinic physician, the neurologist, and the psychiatrist.

The clinic physicians, general practitioners, provided a general medical examination at the time of entry, managed non-seizure related illnesses, treated seizure related cuts, abrasions and fractures, and provided emergency treatment of epilepsy-related situations when the neurologist could not be contacted. On several occasions the general practitioners' effectiveness in handling problems arising from medication toxicity and frequent seizure activity revealed communication and knowledge gaps that could have been resolved if the neurologist's time commitment had been greater or if special training in epilepsy had been provided to the general practitioners.

The neurological consultant had a high level of interest in the Project and a strong commitment to treat and closely follow Project clients. However, the demands of his private practice and his functions as neurological consultant to the entire Center sometimes compromised his role as consultant to Epi-Lab. Thus, some gaps in client treatment and communication with staff were experienced. The neurologist referred several of his private patients to the Project after recognizing its potential benefit for certain individuals.

The neurological consultant's role included the initial evaluation of each entering Epi-Lab client by examination or review of the medical record if a recent examination had been accomplished. He also monitored and adjusted anti-convulsant*

medication. Special diagnostic tests such as the electroencephalogram, anti-convulsant blood levels, CAT scans, etc. were utilized when indicated in individual circumstances. He was also very accessible to Epi-Lab staff in discussing neurological problems as they effected the clients' performance in the Project.

The full-time Epi-Lab staff made a significant effort to maintain close communication with the neurologist, keeping him informed by weekly memorandum of the clients' behavior difficulties, progress in the program, seizure activity, and observations of medication side effects. The neurological consultant expressed the opinion that this information was quite helpful in improving his ability to manage these clients.

In response to a request, the Project psychiatric consultant provided a description of his unique role in Epi-Lab.

PSYCHIATRIC CONSULTANT
Pinckney McIlwain, M. D.

The psychiatric consultant to the Epilepsy Rehabilitation Project performed duties which can be divided generally along the lines of indirect and direct services to the clients of the Project.

Indirectly, the psychiatric consultant, with the psychological consultant and the Project Coordinator, participated in the designing of the overall scheme of the program.

In addition, within his area of expertise, the psychiatric consultant served as a resource person for the non-medical staff within the Rehabilitation Center. This was accomplished through several formal training sessions (See page 9), as well as such formal discussions as were requested. All training was consistent with the philosophy of the Project in the broader sense, that is, a multi-disciplinary approach to the resolution of the clients' problems was more likely to be effective than disjointed service delivery within specific areas of expertise. The achievement of this training goal included indirect attempts to foster communication among and between other members of the Rehabilitation Center staff such as Recreation Therapists, dorm parents, Occupational Therapists, etc., who had direct contact with the Project. The purpose of this was to insure that observations made by the Project personnel were rational assessments of the clients' general level of functioning within the social milieu of the Rehabilitation Center. It was frequently discovered that impressions of client behavior by the Project staff, the psychiatric consultant, and the psychological consultant were in need of alteration when the feedback of these other Center staff was included. The development of these relationships also allowed monitoring of the level of seizure behavior, as well as such adaptive and maladaptive social behaviors as the client might manifest outside of the better control of the Project Work Area.

In a more general sense, it was this area of staff training and facilitating interdisciplinary communication that consultation by the staff psychiatrist (and psychologist) was felt to offer the Project a better return for its dollar investment than that of providing only delivery of direct client service. Traditionally, the psychiatric consultants to the Rehabilitation Center had been involved primarily in the delivery of direct services with very little time available for communication with other members of the Rehabilitation Center staff in regard to the specific clients involved. This communication gap created some feelings of animosity at times and served to further distinguish a given client as having a psychiatric disability in addition to epilepsy. Since psychiatric difficulties are seen to be among the least malleable types of disabilities, such identification frequently colored attempts on the part of staff members to successfully habilitate or rehabilitate the individual client.

Because of this general atmosphere, a key decision was made prior to the acceptance of clients within the Epilepsy Rehabilitation Project. This decision was that the delivery of direct service to the individual clients by the psychiatric consultant was to be limited. This limitation was to consist of involvement solely through an initial screening evaluation (to be described later) and participation in the weekly group sessions. The net effect of this approach appeared to be positive, in that it allowed for more successful client identifications to be made with other members of the Project and Center staff. The limited direct service role, by design, also allowed for only minimal individual client contact thus allowing the psychiatrist and psychologist to serve as group leaders in a more traditional sense. Furthermore, this approach allowed for a more objective evaluation by the consultants of clients' behavior problems as reported by the Project staff.

Direct service involved the psychiatric assessment that was performed on each client at entry into the Project. This was not a traditional psychiatric evaluation aimed at identifying only psychopathologic features as may have been manifested by each individual client. Rather, this evaluation was more a screening tool and a vehicle for allowing the individual client to develop an early non-threatening relationship with the physician, something which in many cases had been lacking in the past. While attempting to accomplish this task, a general screening process was undertaken to determine whether significant psychopathology, i.e., a schizophrenic disorder or a severe affective disturbance, was present in any of the clients who participated. Further, an attempt was made to screen for violence-prone individuals, impulse ridden persons, and other significantly maladaptive characterologic traits for which early identification was viewed to be essential.

Perhaps the most important goal of the psychiatric assessment was the development of an initial understanding of why the individual client had chosen to participate within the Project. In other words, was the individual legitimately interested in

making a somewhat belated re-evaluation of his life's experience and was he or she willing to take this information and use it in a vital meaningful way to effect personal change? Since the population of persons with epilepsy represents a rather high risk group, both from the rehabilitation perspective and from psychopathologic perspective, these questions were felt to be crucial. The initial psychiatric assessment served only as an initial screen, as the answers to these questions were determined not to be static.

The psychiatric assessment was essentially aimed at developing some baseline criteria against which later observations could be assessed. A significant attempt was made to not attach labels or psychiatric diagnoses to each individual client, as it was felt that this would do a disservice in the majority of instances. To label someone as having a psychiatric illness in addition to a seizure disorder would create additional barriers to future employment that would be exceedingly difficult to overcome regardless of the performance of the client within the Project. Since the goals were to assist an individual in leading a relatively normal lifestyle, it was felt that the fewer "strikes" against the individual at the beginning, the better off he would be.

This was not to say that significant psychopathology was avoided. For example, individuals who were violent-prone were ultimately excluded from the Project per se' and channeled into other alternative programs which were deemed to be more appropriate. Though this may have been the most expedient way to handle these problems, it was felt that channeling these clients into other programs also was likely to yield the highest chance for successful outcome for the greater number of clients, rather than a mediocre outcome for the larger number.

In sum, the psychiatric consultant's role enabled him to serve as a resource person who had special skills in the medical sciences, allowing him to communicate forthrightly with clients in regard to specific questions they may have about their disorder. In addition, the psychiatric consultant was expected to screen for significant psychopathology, as previously noted and from his special perspective, develop some thoughts in regard to the possible interventions which might be made with each specific client in their specific treatment protocols.

* * * * *

Many problems were experienced in orienting the Medical Department to the Project and its goals, and in effecting optimal treatment to the clients in the Project. These problems were due primarily to the staff's uncertainty about this new Project and its goals, to the anxieties of many individuals about the nature of the population to be served (uncontrolled epileptics), and to the slowness of the bureaucratic system of the Rehabilitation Center. The following discussion of the problems, accomplishments and recommendations is made in a constructive vein in hopes that findings of the Project will have an impact in the

future for all epileptic clients who become students of this Rehabilitation Center or other similar facilities.

Some of the more profound problems experienced during the Project in medical service delivery were as follows:

1. More neurological time would have been desirable, particularly in attending to the staff training needs of medical staff which became evident during the process of the program.
2. Bureaucratic red tape and communication difficulties made initiation of new procedures such as acquiring routine blood levels and utilizing advanced laboratory procedures such as the EMIT system difficult and untimely. This difficulty of stimulating the bureaucracy to respond to new ideas caused some clients to pass through the program without the benefit of some of the medical services that were available in later classes.
3. Due to limited clinic nursing time which was committed to the Project, charting of neurological data for use by the neurologist was not optimal. Having a nurse assigned to the Project for a specified period of time would have aided greatly in the solution to this problem.
4. In spite of training efforts initiated by the Epi-Lab staff, particularly in regard to the handling of seizure episodes, medical staff performance in handling seizures was inconsistent and often in conflict with policy statements. The tendency was to overtreat the seizures as a medical emergency. It proved to be impossible to establish routine procedures with which all staff would comply in regard to the handling of seizure episodes and other maladaptive behaviors.

In spite of these and other problems which impeded progress, significant accomplishments were made in the overall medical treatment and handling of the person with epilepsy. Some of the major accomplishments are as follows:

1. The Project, through close communication with the neurologist, demonstrated the value of the multi-disciplinary approach in the treatment of seizure disorders. The neurologist commented on many occasions that he was able to contribute more effectively to the treatment of the whole person in a multi-disciplinary program such as Epi-Lab. Whereas heretofore his role in other settings as an isolated physician without counseling, Rehabilitation and psychological support rendered his treatment efforts for some patients less than effective.

2. As a result of the Epi-Lab program, the Center was able to establish a more enlightened approach and procedure to the anti-convulsive management of epileptic clients. Blood level determinations are now much more available and used more routinely.
3. As a result of training efforts conducted by the Epi-Lab staff, overall staff performance in the medical unit in handling seizure episodes has improved. Though not perfect or totally consistent, most seizure episodes are handled in a more facilitative manner in accordance with Center policy statement (See Appendix K).
4. The Epi-Lab staff training of nurses and other medical personnel helped them to reinforce program goals with clients when the clients were receiving treatment or services in the Medical Department. Not only were seizures handled more effectively, but more appropriate responses by medical staff to manipulative behavior such as medication non-compliance, using seizures to get out of work, etc., was reduced. The frequency of staff over-reaction to seizure episodes and manipulative behaviors was considerably reduced. Also, the tendency for clients to utilize medical complaints as manipulations was no longer permitted by staff to the extent that existed prior to the Epi-Lab Project.
5. Those clients which improved in the areas of adaptive behavior were observed by the medical staff to relate more effectively with medical personnel, being less dependent, less manipulative, and more compliant with medication prescriptions.
6. All clients with epilepsy at the Rehabilitation Center are treated differently and more appropriately by the medical staff as a result of the efforts made by the Epi-Lab program.

In spite of the positive strides made in the medical treatment of the epileptic client at the Rehabilitation Center, recommendations for further improvement can be made, especially if this program is continued or if another similar program is established. Some of the recommendations are as follows:

1. More training should be provided to general practitioners, nurses, and paramedical personnel in the management and treatment of the epileptic client.
2. During the Project the need for a full-time nurse to provide patient education and coordination of all neurological treatment was observed. Future programming in this area should include this consideration in planning for staff needs.

3. Neurological consultive time should be used not only for direct patient care, but also for in-direct services of staff training and consultant to staff on special client problems.

OCCUPATIONAL THERAPY - Mary Derstein, O.T.R.

The role of Occupational Therapy in the Epi-Lab Project was to evaluate perceptual-motor skills, self-care skills and simple homemaking skills. The clients treated in Occupational Therapy were selected by the Epi-Lab staff as those exhibiting "problems" following observation and screening in their Work Area. The problems observed in the Epi-Lab Work Area were seen by the staff as incoordination, poor memory, lack of organization, inability to problem solve and often poor hygiene.

The following evaluation tools were used to identify and measure functions and dysfunctions:

1. Bruininks-Oseretsky Test of Motor Proficiency - Short Form
2. Developmental Test of Visual Perceptions (Frostig)
3. Functional Capacities Evaluation
4. Smith Hand Function Evaluation
5. Self-care evaluation, including simple homemaking
6. Southern California Sensory Integration Battery
7. Weschler Memory Scale Form I

Of the above, the most useful evaluation battery found was the following:

1. Bruininks-Oseretsky Test of Motor Proficiency-Short Form
2. Developmental Test of Visual Perception (Frostig)
3. Wechsler Memory Scale Form I
4. Self-care evaluation including simple homemaking

The findings primarily were the same problems found by the Epi-Lab staff. The findings from the evaluation also revealed that those who had seizures over a longer period of time demonstrated greater losses in the areas of perceptual motor dysfunction, including motor planning, problem solving ability, memory, hygiene and ability to function independently in homemaking and dormitory living. In addition, the majority of the clients evaluated were noted to have decreased scores in gross motor skills, standing balance, speed and coordination required to perform fine motor tasks.

Treatment time in Occupational Therapy varied from twice daily, four days a week for 14 weeks, to once daily, four days a week for 2 weeks depending on the involvement of the client. Treatment involved perceptual-motor training to improve the areas of fine motor coordination, figure ground, form constancy, position in space and spatial relationships. Materials used were from Developmental Learning Materials, Dubnoff Program, and Fairbanks-Robinson Perceptual-Motor Development.

Through suggestion and demonstration, the therapists attempted to remediate self-care and hygiene problems. Homemaking skills were taught primarily through repeated demonstration.

Gross motor activities were suggested to the Recreational Therapist for the improvement and/or the development of coordination and basic locomotor skills. A program of elementary sports skills was also suggested to improve socialization skills and self-confidence in motor performance.

RESULTS:

The greatest changes were noted primarily in the areas of improved self-confidence and social skills. Some changes in self-care were noted but were more significant in clients treated for a longer period of time involving much repetition. The problem appeared to be a reluctance to change for an unperceived need. Motor planning and improved coordination for a particular skill were learned through numerous repetitions of the exact procedure.

In conclusion, remediation of the problems was not significant in the short period of time the clients were treated in Occupational Therapy. Although some changes were seen, it was questioned whether a longer treatment time would be beneficial aside from establishing compensatory patterns which could deteriorate if not used frequently.

SPEECH PATHOLOGY

The Department of Speech Pathology was used on a referral basis for those clients who demonstrated communication problems of a receptive and expressive nature. The primary purpose was evaluation, but some interventions were tried with selected clients during trials of speech therapy.

As is described elsewhere (See Counseling section, page 57; Work Area section, page 77; Learning Disabilities section, page 75), deficits in communication were significant barriers to some clients, especially those who displayed functional cognitive and learning deficits. The Speech Pathology Department helped to clarify the problem and its magnitude in those clients. Even though significant changes and improvement were not accomplished as a result of Speech Pathology intervention, the pathologist was able to clarify the problem so that Epi-Lab staff could anticipate individual difficulties and make program decisions with greater knowledge and understanding of the clients' deficits in this area.

The following are the impressions and recommendations of Shirley J. Starkey, the pathologist who worked most intensively with the Project clients:

Impressions: Based on my experiences (8-10 clients), I felt most had some degree of communication deficit. Some communicated and functioned fairly well in the work situation. Others seemed to do fairly well on a surface level, but had real problems, as Epi-Lab staff observations pointed up. Such comments as "cannot follow directions well, does not seem to comprehend and integrate directions and concepts, expresses himself poorly, seems unable to remember" were common. This behavior was not always compatible with test results.

There were problems with our test instruments as most are not standardized for the epilepsy population. The best I could get was generalizations. Testing, however, did point up deficit areas: reduced oral-written language and vocabulary with concomitant lack of verbal facility, reduced memory for more involved directions; reduced recognition vocabulary; and seeming academic retardation. Close scrutiny of two language therapy clients seemed to show specific disabilities such as limited insight and judgement, immaturity, difficulty in modifying perceptions, problems with part-whole, and spatial relationships. Test data and observations led me to believe the clients have medical problems complicated by social and learning disabilities. On a simple or automatic level (routine tasks) one is likely to observe minimal problems. With more complex tasks and problem solving, one may see a breakdown in the problem solving mechanism as a result of deficits in integrative language function. Behavior may be seen as inability to generalize, make logical/rational judgements, and remember a task sequence. One other observation was those clients with diagnosed temporal lobe epilepsy had communication deficits much like those of patients with left hemisphere impairment.

Recommendations:

1. Language testing should be a facet of the program. It provides some information on weak and strong areas in communication.
2. Epileptic clients may require aids to facilitate memory in specific situations, i.e. employment. This may include written and taped instructions.
3. Some clients may not do well on self initiated tasks, but may do better on routine or rote type tasks.

LEARNING DISABILITIES:

RATIONALE:

The Epilepsy Project was designed to develop a methodology for rehabilitation programming for persons with severe seizure

disorders. After extensive program development in the areas of medical management, psychological adjustment, work adjustment, and independent living skills, a significant gap in programming was identified. Indications were that the missing services would be crucial to the eventual outcome for a large percentage of Project clients. Evaluating clients in Epi-Lab through psychological evaluation (including intellectual, personality and neuropsychological when indicated), psychiatric assessment, neurological examination and Work Area assessment resulted in the identification of a significant number of persons (approximately 50% of all clients served), particularly those with temporal lobe seizures, that manifested significant vocational deficiencies in learning and problem solving abilities.

The various labels that described these problems included:

1. difficulty in shifting learning sets,
2. difficulty with immediate visual and auditory memory,
3. diminished rate of new learning,
4. perseveration on a previously learned concept,
5. impaired problem solving ability,
6. problems focusing on relevant detail,
7. memory deficits for immediate and delayed recall,
8. disorientation when forced to rely on proprioceptive and tactile sensory motor cues,
9. perceptual problems-recognizing similar sets,
10. difficulty in formulation of thoughts, and
11. difficulty in developing new problem solving strategies.

The Department of Health, Education, and Welfare (1977) states:

"Specific learning disability" means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia and developmental aphasia"

This is an educational definition used to define specific learning disabilities in children. However, many of the difficulties experienced by the clients in Epi-Lab corresponded with the characteristics of this definition.

Intervention strategies were attempted through the Project psychological consultant, the Center Department of Occupational Therapy, and Speech Pathology, and in the Work Area itself. Successes were very limited. The educational literature was barren in this area with the adult population. However, significant strides had been made with children in an educational setting and there was reason to believe that some of the techniques utilized with children might also have application for this adult population. Preliminary investigations and discussions with various educational and medical personnel pointed toward the field of Learning Disabilities as a possible solution to the programming gap. By communicating with various resource persons, the conclusion was reached that a person with training in learning disabilities should be able to assist in determining the types of interventions that could help a person compensate for these problems.

Thus, a Learning Disabilities Specialist was hired as educational consultant to Epi-Lab to serve during the final Project year for the purpose of intensively intervening in this problem area in order to make a determination as to the effectiveness of educational techniques for remediation or circumvention of organically based learning difficulties. Qualifications of the consultant included:

1. training in learning disabilities at the Master's level,
2. experience in working with epileptic children with learning disabilities, and
3. experience and knowledge of the medical aspects of this disorder, including pharmacological, neurological, behavioral and learning problems.

A 1/3 time commitment schedule was arranged. A portion of this time was spent at Epi-Lab working directly with staff and clients and the other portion was spent in Morgantown doing research, planning and preparatory types of activities.

In order to screen clients for Learning Disabilities programming, discussions were held with almost all Rehabilitation Center counselors, with other departments, and with other non-direct service personnel. It became readily apparent that learning disabilities among Center clients was a prevalent problem and everyone was looking for a "cure." Epi-Lab's purpose was more narrow - to identify the problems more specifically and examine the impact of intervention methodologies on a few select cases. The target population was those clients with organic deficits (as defined by educational, psychological, neuropsychological, psychiatric and Work Area evaluations) who demonstrated

work-related problems of learning and behavior. These people were considered to be most in need of specialized services of an educational consultant.

General goals of this program area were:

1. to attempt to more clearly define the problems that clients manifested,
2. to examine the utility of various intervention strategies;
3. to focus upon the vocational manifestations in a practical, specific manner,
4. to provide input into other program areas in which similar problems were encountered (Recreation, Occupational Therapy, job training, etc.),
5. to gain sufficient knowledge to enable the examination of the utility of continuing this type of programming with this and other disability groups in a Vocational Rehabilitation setting, and
6. to contribute to the vocational potential of clients served in Epi-Lab.

The job duties of the Educational Consultant included:

1. Evaluation of clients - Primarily through observation in the Work area, oriented toward intervention implementation ongoing throughout the clients' program. Testing when indicated.
2. Devising intervention strategies - Targeting problems involving independent work habits and job specific skills. Coordinating with Occupational Therapy, Recreation, vocational training, etc.

Major emphasis in Work Area programming.

3. Staff training - Primarily the Work Area Supervisor.
4. Monitoring of client progress - Directly and by use of charting and other recording formats designed for use by the Work Area Supervisor.
5. Documentation - Report conclusions and results in form capable of being used by other staff.
6. Follow-up - Consult with other departments implementing prescriptive interventions with former Epi-Lab clients previously served by the Educational Consultant.

There were several distinct points of emphasis to the Educational Consultant's theoretical approach to the problem of learning

disabilities in adult Epi-Lab clients. The first point was to decide upon a functional goal and work toward circumventing the learning difficulties that hindered progress toward that specific goal. The ideal functional goal was the specific job for which the client was to be ultimately trained. The justification for this was that assistance in learning would have to be repeated if a less specific goal was chosen because of the tendency for persons with organically based learning disabilities to have difficulty in transferring knowledge to new situations.

The second point of the approach was to concentrate upon circumvention, not remediation of the learning disabilities. Remediation of learning deficits has proven impractical with children. It follows that the remediation of an adult's learning deficits, for example, visual and auditory memory, would be impractical and unfeasible. Often the impracticality involved in remediation is cost, months or years of the clients' time, staff time and limited results. Circumvention strategies, on the other hand, should theoretically be more practical and individualized.

METHODOLOGY:

An examination of the operational methodology used in Epi-Lab to confront problems in learning may be helpful. Once a client was suspected of having a learning disability, it became necessary to clearly define specific deficit areas. Work Area assessments, referral information from Occupational Therapy and Speech Pathology, medical records, and extensive test data were used to do this. Tests such as the Halstead-Reitan Neuropsychological Battery, the Wechsler Adult Intelligence Scale, the Wide Range Achievement Test, and the Durrell Analysis of Reading Difficulty, along with several personality inventories were utilized.

The next step in the process was making a determination of the optimum learning mode and capacity of each client. Each activity in the Work Area was analyzed and broken into its smallest component parts. Written instructions were prepared using these component listings. Then those students with learning difficulties were observed as they worked on these activities to determine learning strengths and weaknesses in a practical situation. These observations, and all other data, were used to form an individualized teaching scheme by which the supervisor could instruct the client or by which the client could receive and store new information. This meant determining such things as the clients' most receptive learning channel; the maximum number of instructions that could be received and effectively processed; learning tolerance level; attention span, and so forth. The teaching scheme had to be structured and consistent, yet be flexible enough to permit each client to progress at an individualized rate. Each person's program was indeed unique.

After identifying a client's learning strengths and weaknesses in terms of specific goals, individual problems were targeted and prioritized. After all, most clients had numerous problems and it was not practical to attempt intervention in all areas simultaneously. Therefore, problems relating to achievement of a defined goal were targeted and prioritized. For example, for one client those problems targeted may have been those that were preventing him from successfully performing one task in the Work Area. The specific difficulties would be prioritized. Each difficulty would then be dealt with in logical order with an effective practical intervention being devised to circumvent that difficulty. Interventions entailed approaching the client through his best learning channel, modifying the work environment when necessary, and using whatever tools or appliances that were necessary to enhance the cognitive process or the physical performance. An understanding of the client's adaptability, motivation, interests and personality were necessary.

For example, one client's evaluation, using the aforementioned techniques, suggested he had low frustration tolerance, poor academic skills, particularly poor reading ability, language deficits, a diminished rate of new learning and impaired problem solving ability. However, he had a prominent strength of good retention of audible information, especially after much repetition. This man had great difficulty performing all tasks in the Work Area. Using this and other information, a teaching strategy was prescribed. This man was taught using verbal instructions enhanced by demonstration and repetition. The supervisor read the instructions aloud, demonstrating each instruction; then the client performed the activity while the supervisor read each instruction aloud to the client. The same words were used by the supervisor each time the instructions were repeated until the activity had been learned. The client did not experience any overt frustration and retention was good.

Objective monitoring of progress was essential. Just as observations were made initially to define the problem, it was necessary to collect further data to determine if progress was being made. Of course, observations were made of the same factors considered initially and were periodic and on-going for a sufficient period of time.

Because this whole issue of learning disabilities in adults was new and virtually unexplored, Epi-Lab's efforts in this area were largely trial and error experimentations. So, each intervention necessitated certain questions being answered. It was necessary to determine if, through interventions tried, the student was making enough progress to justify continuing with that intervention. Any appropriate changes had to be made in the intervention strategy. The agreed upon goals had to be re-examined and priorities re-established. It was most difficult to determine when to move on to the next step. As pioneers in this area, the ultimate problem was determining when interventions became infeasible and impractical to the point that service discontinuation was appropriate.

The final operational objective was follow-up. Learned facts, conclusions, and recommended interventions of an on-going nature had to be reported in a usable form. Any information which would be helpful to a client in other parts of his Rehabilitation program had to be transmitted to the appropriate professionals and departments. For example, information about a client's best learning channels and the mode of instruction that was most effective might be helpful to evaluators, instructors, counselors, therapists and others throughout the person's Rehabilitation program. But the information had to be usable in realistic everyday activities and feasible for use in terms of time, effort and cost.

The Educational Consultant or other Epi-Lab staff had to be available to aid in the implementation of prescribed teaching schemes being implemented with Epi-Lab students in other areas. Interventions were not always smoothly organized, set-up, and implemented, so flaws had to be worked out. Follow-up was also seen as necessary because other personnel needed help in using a new approach to teaching this difficult population.

Throughout the planning, evaluation, interventions, and follow-up, the emphasis was on the long-range objective of developing a possible way to approach the problem of learning disabilities on a broader base. The intention was to find a way to serve epileptic clients and other disability groups at the West Virginia Rehabilitation Center who manifested specific learning disabilities.

DISCUSSION - PROBLEMS AND RECOMMENDATIONS

This whole area of programming with the Epilepsy Project had some significant problems. From the initiation of this part of the Project, time was a foe. When the Epi-Lab Project was conceived and established, learning disabilities was not one of the problems anticipated or prepared for in the effort to comprehensively serve and meet the needs of the uncontrolled epileptic person. By the time the gap in services was recognized and an attempt was made to fill the void, it was the third and final year of the Project Grant. The format and direction of the Project was molded, working relationships were formed, and there were only six to nine months of client service remaining. Therefore, there was a definite urgency in the efforts to develop a viable learning disability program.

These constraints limited the time available to recruit and orient an Educational Consultant.

Equally effected were the clients with the learning difficulties because they had either moved on to another facet of their Rehabilitation program outside of Epi-Lab, or were so far into their Epi-Lab program that the Educational Consultant did not have adequate time to intervene in their learning situation.

The urgency of developing a program in this area also

affected the staff's ability to systematically gather pertinent data and materials, organize these, formulate a program, test the program, and make necessary changes. Therefore, what resulted was, in some respects, inconsistent, unstructured, and less than well defined.

Knowledge gaps also contributed to the less than satisfactory results achieved in this area of programming. The Epi-Lab full-time staff and, to some degree consultant staff, was unfamiliar with the learning disability subject because staff expertise was not in this field. In spite of extensive efforts to acquire relevant knowledge, adequate resources, especially those needed to determine alternative approaches to these types of problems, were not found. On the other hand, the Educational Consultant, by virtue of her education and employment history in the learning disability field, had expertise in the educational setting, but lacked knowledge of the Vocational Rehabilitation process and system. This limited her ability to apply classroom approaches to vocational work settings. The Consultant lacked an understanding of the inter-relationship of field offices and the Rehabilitation Center, and of the internal workings of both of these entities. Relevant issues like the logical progression of the Rehabilitation Center process from admission to job placement had to be learned.

Even more of a liability was the lack of helpful information on the subject of learning disabilities in adults available to both Epi-Lab staff and the Educational Consultant. The literature was barren; and there was no experience with this population to draw upon. A screening instrument beyond tests used with children could not be found and a systematic approach to program intervention strategies could be established only by a trial and error method.

An attempt was made to resolve these difficulties by drawing on the knowledge of other programs. For instance, the Educational Consultant and the Work Area Supervisor visited the Jewish Vocational Center in Cincinnati, Ohio to study the "Learning Capacities Program." This was a program for adult handicapped individuals in various centers throughout the State that exhibited vocationally related problems in learning. The primary goal of this trip was to acquire knowledge of their screening techniques, but these proved to offer little more than the evaluation resources already available to Epi-Lab.

Other Rehabilitation Center departments were consulted, particularly Occupational Therapy and Speech Pathology and they became valuable resources for evaluative information. But, they also lacked information that was necessary to assist in developing effective intervention programs.

There were other problems also. The Work Area was the sight for practical observations of and hands-on interventions with those clients with learning deficits. However, the design of the Work Area did not always favorably coincide with efforts in the new

area of programming. Despite de-emphasis of production, there were some demands. Contracts had to be met. Therefore, significant numbers of students could not be pulled off certain activities for long periods of unscheduled time. This need to maintain the flow of activities in the Work Area often interfered with intervention strategies in the learning area. In addition, the number and types of contracts in the Work Area were limited. For example, if a new learning experience was needed to test processing of new information, a fresh work activity may not have been available because of limited contracts during that time period.

The approach to data collection and intervention implementation was inappropriate for the setting. The Work Area Supervisor was responsible by role definition for evaluating, teaching, and supervising all students in the Work Area. Also, there was the obligation to give appropriate feedback to students about their progress, record information, and write reports. With the hiring of an Educational Consultant came the duties of aiding the Consultant in her efforts to circumvent the learning problems of Epi-Lab clients; this necessitated becoming trained in learning disabilities, evaluation and circumvention. The responsibilities placed on the Work Area Supervisor became overwhelming. After all, not all students had specific learning disabilities, but did have individual needs and goals.

The research oriented approach to gathering data and monitoring progress also conflicted with the goals of the Project. Baseline data was to be collected, often for weeks, during which time no feedback could be given on that particular behavior. This conflicted with the original Project philosophy of giving timely, appropriate feedback to clients. Secondly, once an intervention began, it had to continue for a period of time, even though negative behavior was resulting. Sometimes these interventions removed the responsibility for independence from the client and placed it upon staff or co-workers. This was in direct conflict with Project philosophy.

As stated earlier in this section, the Educational Consultant had a 1/3 time commitment to the Project. This was an insufficient amount of time in which to effectively deal with so serious a problem. The person with the expertise was too far removed from daily activities. This might not have been as necessary if the Work Area Supervisor had received the training proposed in the Educational Consultant's job description.

The Educational Consultant being accessible only periodically for short periods of time also created an unnatural "special helper" relationship between clients and the consultant. Other clients became jealous because they did not receive these services.

Two other problems existed and these probably have the greatest implications for any similar efforts undertaken in the future in the area of learning disabilities. First, the role of the Educational Consultant lacked operational clarification. Both the consultant and full-time staff held theoretical concepts of what

the role should be, but these were not in accord. The consultant's attempts to define the role fluctuated to the extent that the interdependence and independence of disciplines could not be clearly delineated. It is known that Epi-Lab's expectations of this role were not met in that most evaluation and intervention strategies were devised and implemented by Epi-Lab full-time staff, Occupational Therapy, or Speech Pathology rather than the Learning Disabilities Specialist. The coordination of specific learning disabilities information with other departments was lacking and the staff training that was needed to fill the gaps was minimal. Moreover, a structured logical approach to learning disabilities was not formulated. The inability of an educator of children to adapt to and function in a vocational setting comprised of adults probably accounts for these difficulties.

Secondly, the consultant's concept of the role did not allow for the flexibility and adaptability required to pioneer a new program area in an established Vocational Rehabilitation setting. The target population and the general goals agreed upon initially were not those accepted by the Educational Consultant during implementation of this service area in the Project. Epi-Lab's original objective was the clarification of the problem of organically based learning disabilities in adult handicapped clients. The program emphasis was the formulation of an approach for use with epileptic clients and other disability groups in the Rehabilitation Center that were manifesting these difficulties. The objective was not pure research or even individual client service. Efforts had to be attempted in a way that served the interest of Vocational Rehabilitation and followed operational guidelines thereof.

SUMMARY:

In summary, the problem of learning disabilities in adult epileptics was and is a problem for the researcher not the practitioner, yet. The Epi-Lab design did not allow for the research model which was necessary to investigate this problem. Research expertise was lacking in all staff involved. But in spite of the Project's inability to reach the desired goals of this part of the program, some accomplishments were made and are as follows:

1. There is now professional substantiation of the problem of learning disabilities in adult epileptic clients. The problem does exist at the Rehabilitation Center and appears to be prevalent, especially with the organically impaired. The problem has been defined educationally and vocationally as well.
2. Epi-Lab has estimated the degree of interest in this problem not only in Epi-Lab, but in the Sheltered Workshop, Vocational Evaluation, the therapies and in training areas. Many staff are looking for a more effective way of serving clients that have learning problems in addition to other disabilities. Research of available

resources indicates that available interventions are but trial and error.

3. Probably the greatest accomplishment derived from the attempt to provide services to these clients with learning disability problems is the fact that there is now a better understanding of why many of these uncontrolled epileptic clients have failed vocationally. It was not always just seizures, though this may have been a contributing factor, but indications are that many could not successfully learn and perform. These learning disabilities are a very significant reason for failures in school, employment and the Rehabilitation system. The truth is that despite the fact that specific learning disabilities do represent a substantial handicap to employment, neither the Rehabilitation system, nor the Center is structured to provide services that will make a significant difference to the vocational outcome of these people. At the Rehabilitation Center these individuals still generally underperform on standardized vocational evaluation batteries such as the J. E. V. S., still are unable to fully benefit from counseling and other abstract services, and still are left to be trained in the routine training areas such as janitorial, if at all. Despite the fact that Epi-Lab did not find the answer to the problem of learning disabilities, it did design a better means of evaluation. The Epi-Lab approach to evaluating these clients not only offers documented information about an individual client's learning capacity, and best learning channel, but gives indications of successful intervention strategies to aid the client in vocational performance.
4. Epi-Lab's disappointments have given a clearer indication of the requirements necessary in an Educational Consultant advising in the area of learning. The person
 - a. needs medical knowledge of the disability group(s),
 - b. needs a working understanding of the Vocational Rehabilitation system,
 - c. needs to be full time,
 - d. needs to be trained in observing and monitoring behavior,
 - e. needs a Learning Disability or Special Education background,
 - f. needs an understanding of job modification, and
 - g. needs supervisory and planning capabilities.
5. Investigation in this area has brought to light many resources already available to Vocational Rehabilitation.

These resources could very well serve as a new beginning in the formulation of services. First, there is the availability of the Research and Training Center to assist with the necessary research design and data collection and analysis. Secondly, there is an expressed interest by the Occupational Therapy and Speech Departments to work with the organically based learning impaired. Of course, both these departments already have knowledge and experience within their disciplines from which to draw. Thirdly, there is access to numerous testing instruments that could be used in the evaluation process. Fourth, there is a master's level special education employee in the Speech Department at the Rehabilitation Center. Fifth, of course, there is access to all available literature and findings on learning disabilities in children from which techniques might be borrowed.

CONCLUSION:

The problem of organically based learning problems in the epileptic population does exist and is prevalent in the adult age groups, as well as children. The Epi-Lab Project attempted an intervention strategy using an Educational Consultant, but the results were not wholly satisfactory. However, future prospects for more adequate services in this area are not totally bleak. More resources have been identified, the problem is more clearly defined, and some practical experiences have laid the groundwork. The Vocational Rehabilitation Agency needs to formulate a viable approach to the problem, thereby filling the gap in services to this severely disabled group of individuals.

TRANSITION MODEL

The Epi-Lab program, as originally structured and operated through the first five classes, proved to be a valuable model for programming clients and deriving maximum benefit both from a client change standpoint, and from a learning standpoint. However, during November and December of 1978, it was realized that several problems existed which would preclude continuation of the program in this fashion and a new model was proposed and implemented in January 1979.

The problems which were interfering with program continuation in the first model were lack of sufficient appropriate referrals; the slow movement of clients through the Epi-Lab unit which reduced the number of clients that could be taken into the program; difficulty in establishing criteria for exiting clients from the program; high incidence of aggressive and violent behavior which, when it occurred, undermined other program goals for all clients in Epi-Lab, and excessive concentration of program within the Epi-Lab unit to the exclusion of other Center services.

These problems provided an incentive for a reassessment of

the program delivery system and the knowledge gained through it during the period in which it was used. It was determined that the program could be restructured to improve client services, to improve the definitiveness of decision making in regard to continuation or termination of a client's program, and to enable utilization of the unit by larger numbers of clients from all areas of the Rehabilitation Center. Thus, the transition model was developed and implemented for the last two classes. This model was considered to be appropriate for inclusion in future plans for programming continuation for epileptic clients at the Rehabilitation Center.

The transition model was designed to be a Center-wide program of services for epileptic clients with the goals of:

1. Applying the knowledge gained through experience with severe epileptic clients during the first five classes of Epi-Lab.
2. Promoting the positive aspects of programming while discarding the negative aspects which were non-productive,
3. Increasing the number of clients being served per period in Epi-Lab, and
4. Conventionalizing the program so that it fit into the existing Center structure and contributed to the services being provided to other epileptic clients, as appropriate.

The model contained two major components; the evaluation component and the service component.

1. Evaluation: The evaluation component was intended to utilize the expertise and unique service areas of Epi-Lab, its staff and consultants, to thoroughly evaluate in a multi-disciplinary fashion, the potential of severe epileptic clients. It was intended not to duplicate existing vocational evaluation or work adjustment programs, but to supplement these programs with unique areas of knowledge contained in the Epi-Lab program. The evaluation was conducted for a 30 day period and concentrated in the following areas:

A. Behavioral-Psychological Problems:

Psychiatric examination and psychological evaluation, in addition to the gathering of behavioral observations in the Work Area, were designed to define problem areas and suggest interventions which might be possible in the Epi-Lab or Rehabilitation Center setting.

B. Medical Problems:

Seizure related problems of frequency, diagnosis,

medication dosage, and side effects were investigated by providing a thorough neurological assessment when necessary. Other medical diagnostic services such as blood levels, CAT scans, EEG's, etc., were utilized when necessary.

C. Neuropsychological Problems:

Deficits of perception, coordination and cognition were considered with each client and referrals made to Department of Behavioral Medicine for a Halstead-Reitan when appropriate.

D. Adaptive and Interpersonal Skills:

Psychological evaluation and the observation of social behavior, appropriateness, self-defeating behaviors, assertiveness, adjustment to disability, etc. in Work Area and Group activities defined areas of concern.

E. Communication Skill Deficits:

Work Area observations targeted problems in this area and referrals were made to Speech Pathology when appropriate.

F. Overall Potential for Epi-Lab Programming:

General potential of the client to derive benefit from the program was addressed, in addition to individually assessing the above speciality areas.

The 30 day evaluation program was intended to thoroughly assess those unique problems experienced by clients with severe epilepsy and to look realistically at service opportunities for change which existed within the Epi-Lab unit itself and other service areas of the Rehabilitation Center. The thrust was toward realistic planning with decisions being made at the end of the 30 day period regarding program continuation or discontinuation.

Experience with this model suggested that it significantly reduced the perpetuation of client services for those clients with limited potential and few appropriate goals. This enabled staff time and programming efforts to be expended more appropriately with those clients having greater potential. The following description of the Work Area evaluation unit describes in more detail the specific methodologies employed in the Work Area component of the evaluation unit and how other specialities were used to assess work-related problems.

A small group of clients (4-6) was programmed in the Work Area for three weeks, after Center orientation and group testing.

Emphasis was upon multi-handicapped, severely disabled epileptic clients who had unique problems associated with their epilepsy.

Each received:

1. A structured orientation to the Work Area
 - a. purpose
 - b. individual goal
 - c. rules
2. Introduction to tasks

Evaluation - An assessment of an individual's vocational and personal strengths and weaknesses was made. A breakdown of the evaluation is presented in Table 7.

Prescriptive Report - Interventions and Implementation

1. A strategy for intervening in vocationally significant areas was included, along with suggested means of implementation.
2. Follow-up was essential. Project staff offered to consult with those attempting to implement any intervention strategy in Workshop, vocational training, and Vocational Evaluation.

Recommendation - Sequencing

A recommendation suggesting the logical sequence for flow of services was given based on the Work Area evaluation and all information received from outside evaluation sources.

Recommendations included:

Occupational Therapy
Remedial Education
Work Adjustment (Workshop)
Vocational Evaluation
Epilepsy Class
Group Therapy
Independent Living Programming
Job Training
Recreation
Neurological Evaluation and Treatment

2. Service: The second major component of the transition model of Epi-Lab was service which was intended to provide intervention services on a Center-wide basis to epileptic clients who experienced specific problems and who were determined to have

potential for benefit from particular program areas. All epileptic cases at the Center were screened by the Project staff; some through additional psychological or psychiatric assessment by Epi-Lab consultants in order to determine their ability and motivation for programming within the unit. Additionally, clients who had completed the evaluation phase and who were recommended for program continuation were assigned to other units such as vocational training or sheltered workshop and participated in Epi-Lab intervention services on a part-time basis.

TABLE 7

AREAS OF ASSESSMENT	HOW ASSESSED IN WORK AREA	*OUTSIDE EVALUATIVE RESOURCES
Basic work habits/independence	Rating Scale	
Learning capacity	Screening	Learning Disability Specialist
Vocationally appropriate behaviors	Rating Scale	
Disability related factors	Observations Epilepsy Quiz Mooney Problem Checklist Diagnosis and Medical Form	Neurological Consultant Behavioral Medicine Special Testing
Perception Coordination	Observation in Work Area	Occupational Therapy
Communication skills	Observation and Testing	Speech Pathology
Interpersonal skills/peers and supervisor	Observation	
Ability to follow instructions	Observation Rating Scale	
Functional academic skills	Observation WRAT	Testing
Motivation and attitude factors	Observation	
Psychological needs	Observation Testing	Psychological Evaluation Psychiatric Evaluation
Need for Epi-Lab Intervention	Epilepsy Quiz Psychological Screening Other	Learning Disabilities Specialist Psychological Psychiatric Consultants

*When particular problems were observed in the Work Area, clients were referred for specific evaluations by consultative staff (Learning Disability Specialist, Psychological, Psychiatric, or Neurological Consultants), Department of Behavioral Medicine, Occupational Therapy, Speech Pathology.

Thus, through this component, the Epi-Lab became a service unit to the Rehabilitation Center similar to other departments such as Speech Pathology, Occupational Therapy, Physical Therapy, etc. Specific service areas were defined and a methodology developed for determining appropriate referrals for these program areas. The following is a listing of Epi-Lab services which were provided:

- I. Epilepsy Class I - All Center students who had epilepsy and could benefit from a greater understanding of their disability were candidates for this class.
- II. Epilepsy Class II - Those clients with epilepsy who demonstrated vocational potential and who needed concentrated effort in the areas of self-assertion, self-advocacy, self-help, job interviewing skills, and management of self and epilepsy in an independent living situation were screened for this class.
- III. Group Therapy - This service was available for those clients who were identified through a screening procedure as having the need for this type of intervention and who could be expected to benefit from it.
- IV. "Advanced" Group - This was a group for those clients exiting Epi-Lab programming or the Center facing problems relative to community re-entry and separation from the Rehabilitation Center.
- V. Neurological Evaluation and Treatment - Clients having problems of seizure control, medication side effects, learning difficulties, etc., were referred for detailed neurological investigation and intensive follow-up. Clients were identified through Epi-Lab evaluation or referral from other Center departments.
- VI. Recreation - All clients were referred to Recreation staff which interviewed each in regard to need for individual programming. Recreation staff observed clients in evening activities and made recommendations to Epi-Lab staff in regard to needs and problems.
- VII. Individual counseling for specific problems - Clients were accepted on a referral basis from other Center departments for individual counseling by Epi-Lab staff.

All services were provided by Epi-Lab on a contractual basis for individual clients with firm expectations in regard to attendance and participation.

CONCLUSIONS AND RECOMMENDATIONS:

The transition model was implemented in the last two classes of Epi-Lab with varying results. Some of the problems which provided impetus for the design of this model were solved

and some were not. Referrals to the program from the field were adequate but difficulty was experienced in securing cooperation from Center counseling staff in referring clients to the program. These problems may have been due to the newness of the program, the counselors' lack of understanding of program goals in spite of educational efforts, counselor lack of awareness of special needs of epileptic clients in spite of educational efforts, or lack of client motivation and interest in addressing psychological or behavioral related problems which do not, in their view, cause them great difficulty.

The transition model was considered to solve admirably the problem of excessive program concentration and enabled more effective and expeditious utilization of other Center services. The clients who were ready for training were able to enter training more quickly and those that had no potential were able to exit the program without wasting undue time. However, it is suspected that in the future if numerous clients are served in a model such as this, some whose potential could not be demonstrated during the 30 day period might suffer as a result.

One of the major disadvantages of the transition model was that it did not allow the staff ample opportunity to observe the clients' ability to benefit from the various interventions during the brief period of time. Experience during the first five classes with the original program model dictated that some clients began to derive benefit only after 30, 60, or 90 days of programming.

The final assessment of the transition model was that it provided a promising method of service delivery to enable the Rehabilitation Center system to meet the unique needs of all epileptic clients, especially those experiencing more severe difficulties in areas of seizure management and psychosocial problems. However, successful implementation of this model will depend upon the availability of specialized staff who are knowledgeable in the problems of epilepsy and the additional training of other Center staff, primarily counselors, who must recognize the unique problems of the epileptic client and make appropriate referrals of those clients who could benefit from specific programming components.

CHAPTER V

DESCRIPTIVE DATA ON CLIENTS SERVED

Interview Information: The population served by Epi-Lab is described in the following breakdown of the demographic, medical and test data for all 28 clients served in the full program. This analysis is based upon objective data gathered when each client entered the program.

CHARACTERISTICS OF POPULATION SERVED

DEMOGRAPHIC:

TABLE 8

SEX (N=28)

	Number	Percent
Male	14	50%
Female	14	50%

An equal number of males and females participated in Epi-Lab.

TABLE 9

MARITAL STATUS (N=28)

	Number	Percent
Married	3	10%
Divorced	3	10%
Separated	2	7%
Never Married	20	71%

Most clients served in Epi-Lab had never been married (71%) or were divorced or separated (17%). Several other clients that were married were identified in the referral process, but the necessity of leaving the family to come to the Rehabilitation Center for services created unresolvable problems. Thus, the location of the Project in a residential institutional setting was a deterrent to participation for some potential clients who were married.

TABLE 10

HIGHEST GRADE COMPLETED (N=28)

Grade	Number	Percent
0	1	3%
8	4	14%
9	2	7%
10	2	7%
11	2	7%
12	15	53%
13	2	7%

A majority of clients (60%) had completed 12 or more years of schooling yet were not employable at time of entry.

TABLE 11
AGE RANGE (N=28)

Age	Number	Percent
18 - 21	10	36%
22 - 25	7	25%
26 - 29	6	22%
30 - 33	2	7%
34	1	3%
48	2	7%

The great majority of clients served were young and of employable age.

TABLE 12
VOCATIONAL REHABILITATION
TERRITORIAL DISTRICTS - WEST VIRGINIA

District	Number	Percent
1	8	28%
2	3	10%
3	7	25%
4	5	17%
5	4	14%
6	0	
7	1	3%

Table 12 above presents a breakdown of clients served according to Rehabilitation Districts in West Virginia.

TABLE 13
PRIMARY DISABILITY CODE AT ENTRY

	Number	Percent
Epilepsy (630)	27	96%
Depressive Neurosis (510)	1	3%

Table 13, as expected, indicates that upon referral to the Project the clients' field counselor had considered their primary disability to be epilepsy.

TABLE 14
SECONDARY DISABILITY CODED BY
FIELD COUNSELOR PRIOR TO ENTRY

	Number	Percent
Psychiatric Disorder (510)	4	14%
Personality Disorder (522)	1	3%
Mental Retardation		
Mild (530)	2	7%
Other (699)	3	10%
Epilepsy (630)	1	3%
None Listed (999)	17	60%

The above table indicates that upon entry 17 clients were considered to have no secondary disability. Many of these clients, after further evaluation in Epi-Lab were found to have various types of learning disabilities, behavioral problems, organic-cognitive functioning problems, etc. This finding points to the value of a thorough, intensive evaluation beyond the diagnosis of epilepsy in order to thoroughly understand the client's assets and deficits.

TABLE 15
SUPPLEMENTAL SECURITY INCOME STATUS
(N=28)

Status	Number	Percent
Not an applicant	11	39%
Applicant - allowed	10	35%
Applicant - denied	5	17%
Applicant - status of application pending	1	3%
Not known if applicant	1	3%

Approximately 1/3 of the clients were receiving SSI upon Epi-Lab entry. Several of the clients who had not applied were made aware of this benefit and, as a result, applied and received SSI during their Epi-Lab services.

TABLE 16
SOCIAL SECURITY DISABILITY INSURANCE
STATUS (N=28)

Status	Number	Percent
Not an applicant	19	67%
Applicant - allowed	4	14%
Applicant - denied	5	17%

Only four (14%) of Epi-Lab clients were receiving Social Security Disability Insurance. Most could not qualify because of insufficient work history.

TABLE 17
AMOUNT OF THIRD PARTY INCOME
PER MONTH (SSI, SSDI, VA, ETC.)
(N=28)

Amount	Number	Percent
0	12	43%
1 - 100	4	14%
101 - 200	7	25%
201 - 300	3	10%
301 - 400	1	3%
401 - 500	1	3%

More than half (67%) of entering Epi-Lab clients were receiving some form of third party income.

TABLE 18

PREVIOUS VOCATIONAL REHABILITATION SERVICE			PREVIOUS CENTER SERVICE		
	Number	Percent		Number	Percent
Yes	24	86%	Yes	5	17%
No	4	14%	No	23	82%

The above table indicates that while most clients had received Rehabilitation services prior to Epi-Lab, most had not been at the Rehabilitation Center previously. For many of the clients who had been served previously by the Rehabilitation Agency, services which effectively met their needs or evaluated their condition successfully were not available. To many field counselors the Epi-Lab program was considered to be a "last resort."

TABLE 19

NUMBER OF JOBS PREVIOUSLY HELD
BEFORE EPI-LAB ENTRY
(N=51)

Jobs Held	Clients
0	7
1	6
2	4
3	8
4	2
5	1

The 28 clients served in Epi-Lab held a total of 51 jobs. Seven of the clients had never worked. Six had held 1 job; four had held 2; eight had held 3, etc. Thus, it would appear that the group as a whole had attempted, and in some cases, held a considerable number of jobs and had become unemployed for reasons described elsewhere.

TABLE 20

TYPES OF TRAINING FOR JOBS HELD
(N=28)

Training	Number	Percent
Vocational School	3	10%
On-the-Job Training	16	57%
College	0	
Business School	2	7%
No Employment	7	25%

Only 17% of the clients had received formal training for employment in a business school or vocational school. Most clients who had worked, 57%, had the benefit of on-the-job training in jobs which did not require previous formal training. As could be expected, most of these jobs were entry level, routine, unskilled jobs.

TABLE 21
REASONS FOR JOB SEPARATION
(N=51)

Reasons	Number	Percent
Attendance (due to medical)	5	10%
Pay	0	
Hours	0	
Supervisor's attitude	7	14%
Lacked ability	6	12%
Behavior problem	9	18%
Business decreased	4	8%
Better job	4	8%
Other	16	31%

According to counselor judgement based upon the clients' self-report of reasons for job separation, most jobs the clients held prior to Epi-Lab entry were lost because of a behavior problem, inability to perform in the job, or a negative attitude by the supervisor.

TABLE 22
JOB SEPARATION DUE TO SEIZURES
(N=51)

	Number	Percent
No	35	69%
Minor consideration	1	2%
Major consideration	4	8%
Other reason stated for separation	11	21%

Most of the reasons stated for losing jobs had nothing to do with seizures. But, in the opinion of the clients, 31% of jobs were lost because seizures were some consideration.

MEDICAL INFORMATION:

TABLE 23
TYPE OF SEIZURES

	Number
Generalized tonic-clonic	12
Partial complex with "psychomotor" symptomatology	8
Partial complex - compound forms	2
Combined form	2
Partial - secondarily generalized	1
Partial - secondarily generalized with motor symptoms	1
Partial - elementary with autonomic symptoms	1
Generalized - akinetic	1

The above table indicates that the most frequent type of epilepsy was generalized tonic-clonic (grand mal). It is significant, however, that 15 clients had, as part of their diagnosis, psychomotor or partial seizures in some form.

TABLE 24
SEIZURES FREQUENCY/MONTH
(N=28)

Frequency	Number	Percent
Less than 1	3	10%
1-5	11	39%
6-10	1	3%
11-15	4	14%
16-20	2	7%
20+	7	25%

One of the criteria for entry into Epi-Lab was "frequent" seizure activity. As the above table indicates, this was difficult to determine and varied greatly between clients. The above table is the best estimate possible utilizing the clients' self-report and information contained in the case folder upon entry. Seizure frequency varied with the individual and was always an elusive statistic. However, the above table does indicate that seizure activity was present in all clients and, thus, they could all be considered in one degree or another to have been under poor seizure control.

TABLE 25
ETIOLOGY OF SEIZURES
(N=28)

	Number	Percent
Idiopathic	17	60%
Traumatic	4	14%
Other	7	25%

The above table documents the difficulty in determining causes of seizure disorders. This is consistent with other studies which characterize the majority of seizure conditions as having an idiopathic origin.

TABLE 26
INTELLIGENCE LEVELS
(WAIS FULL SCALE IQ)

IQ Range	Number	Percent
60-70	1	3%
70-80	1	3%
80-90	8	32%
90-100	12	48%
100-110	1	3%
110-120	1	3%
120+	1	3%
Tests not available	3	10%

(Mean 92.71, SD 10.59, Range 63-121)

One of the screening criteria for Epi-Lab was an IQ within the average range. The above table reflects the degree to which the program adhered to these initial screening criteria. The above intelligence quotients were derived in a majority of cases by the Project psychologist after Epi-Lab entry. With this high level of intelligence, it would be expected that more successful outcomes in terms of entry into training and employment would be expected. However, due to the multiplicity of other problems in this population, intelligence was not a good indicator of program success.

TABLE 27
ACHIEVEMENT LEVELS (WRAT)
(N=28)

READING			SPELLING		
Grade Level	Number	Percent	Grade Level	Number	Percent
1 - 2	0		1 - 2	2	7%
3 - 4	1	3%	3 - 4	4	14%
5 - 6	7	25%	5 - 6	6	21%
7 - 8	7	25%	7 - 8	8	28%
9 - 10	5	17%	9 - 10	3	10%
11 - 12	2	7%	11 - 12	2	7%
13 - 14	5	17%	13 - 14	1	3%
14+	1	3%	Tests not available	2	7%
Tests not available	2	7%	(Mean 7.1, SD 2.95, Range 1.1 - 14.0)		
(Mean 9.2, SD 3.0, Range 4.2 - 15.3)					

ARITHMETIC

Grade Level	Number	Percent
1 - 2	1	3%
3 - 4	8	28%
5 - 6	15	53%
7 - 8	1	3%
9 - 10	0	
11 - 12	1	3%
Test not available	2	7%

(Mean 5.6, SD 2.2, Range 0 - 12.8)

The above table, which displays Wide Range Achievement Test breakdown among the population, indicates the broad disparity in ability levels in basic academic areas. A great majority of clients, 69%, were reading above the 7th grade level and could thus be considered to be able to read on a level necessary for everyday existence. However, most clients, 84%, had math levels below the 7th grade, thus pointing to a major deficit area in the population.

REFERRING COUNSELOR DATA:

TABLE 28

REFERRING COUNSELORS' DEGREE (N=21)			REFERRING COUNSELORS' YEARS OF EXPERIENCE		
	Number	Percent		Number	Percent
Rehabilitation Affiliated	15	71%	0-3	1	5%
Non-Rehabilitation Affiliated	5	24%	4-6	2	9%
No degree (case-aide)	1	5%	7-10	8	38%
			10+	10	48%

It is noteworthy that the great majority, 71%, of counselors referring clients that were accepted to Epi-Lab had Rehabilitation affiliated degrees such as Rehabilitation counseling, social work, counseling and guidance, psychology, etc. 86% of these counselors had seven or more years of experience with the Rehabilitation Agency.

Many interpretations could be made of these statistics, but it would seem that very generally speaking, counselors with Rehabilitation training and with long years of experience would be more inclined to be aware of new services and be oriented to referring clients to the Rehabilitation Center.

COMMON PROBLEMS:

Of course, considerable information about the clients was obtained after program entry. Much of this is contained in other sections of this report which describe various program areas. However, several important questions which further delineate these clients can be answered by an analysis of the Rating Scale (See Appendix M) and include:

1. "What were the problems most frequently experienced by all clients?" -- An analysis of staff ratings (See Appendix M) points toward specific problems which were characteristic. For example, most clients, in the opinion of those staff who rated, had deficits in the following areas:

Independence behaviors such as:

Settling quickly into new situations
Planning and completing work with supervisor's aid
Making independent decisions

Acceptance Skills including:

Behaving appropriately for the situation
Presenting a favorable appearance
Relating effectively with both staff and peers

Motivation and Attitude concerns including:

Demonstrating level of confidence equal to abilities
Acknowledging problem areas
Striving for improvement.

Other issues and problems which were highly important for some clients included lack of emotional control, inability or unwillingness to comply with medication schedule, difficulty in perceiving and acting on problem areas, and inadequate basic work behaviors such as maintaining positive attitude toward task, accepting supervision, showing initiative, etc.

This brief discussion of the rating information serves only to point out that a multitude of problems beyond uncontrolled seizures were manifested in this population and provide further evidence defining the characteristics of their maladaptive lifestyles. The reasons for their unemployment are evident.

A more detailed presentation of the rating data is contained in Appendix M.

CHAPTER VI

OUTCOMES

The purpose of the Epi-Lab client program was to have an impact upon clients and hopefully improve their lives in various areas such as vocational functioning, psychological adjustment, acceptance of self, independent living, and overall life adjustment. Each client possessed individual potentials and it was hoped that the program could maximize these potentials. The total impact of Epi-Lab on the clients it served cannot be fully determined at this time because change will continue to occur in their lives. Some will continue to improve and some will regress; some may require continuation of services by Vocational Rehabilitation or another agency, and some may be able to live independent lives.

Since Epi-Lab was not a strictly controlled research study, objective measures of client change and outcomes, except for some psychometric data, are not available. Thus, several methods have been utilized to show client change and present the status of all clients at the end of the program. The methods utilized include:

1. a presentation of the program status of all clients at the close of the client program,
2. an analysis of the results of the questionnaire sent to all clients served in the program, and
3. a presentation of six illustrative case summaries.

PROGRAM STATUS OF ALL CLIENTS AT PROJECT END:

The following information is based upon the program status of each client who was served in Epi-Lab as of April 12, 1979, the date that the Project discontinued serving clients. Data in each category is presented followed by an explanation of the criteria and definitions utilized in each category.

TABLE 29

COMPLETED EPI-LAB

	Number	Percent
YES	18	64%
NO	10	36%

Sixty-four percent of the clients entering Epi-Lab were

considered to have completed the program. A client was considered to have completed Epi-Lab when some standard of accomplishment was met, or active participation was judged to be fitting to the individual client. This included displaying motivation to improve or experiencing actual improvement in the number of phases that the client participated in the Epi-Lab unit itself. Most clients who were judged to have completed Epi-Lab did not voluntarily withdraw, did not involuntarily withdraw for disciplinary or other reasons, and were considered to have "stuck it out" and tried their best even if little was accomplished.

The fact that 64% of the clients were considered to have completed Epi-Lab is significant when it is considered that the majority of clients were leading relatively sheltered, dependent, non-productive lifestyles prior to entering Epi-Lab. The great demands placed upon them included leaving their home, coming to the Rehabilitation Center and participating in a very rigorous program which threatened their dependent, comfortable existence at home. The fact that 18 clients stayed attests to their courage and determination to improve their life situation.

TABLE 30

NUMBER OF WEEKS IN EPI-LAB

<u>Weeks</u>	<u>Number of Clients</u>
1-4	10
5-8	5
9-12	2
13-16	1
17-20	1
21-24	6
25-28	0
29-32	2
33-34	1

N=28

The above table specifies the number of weeks spent in the Epi-Lab Work Area and other full-time programming. It does not include the number of weeks that the client spent in other Center service programs, such as Vocational Evaluation, training, or Sheltered Workshop, while attending Epi-Lab Groups or classes on a part-time basis.

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TABLE 31

NUMBER OF CYCLES COMPLETED

<u>Cycles</u>	<u>Number</u>	<u>Percent</u>
0	8	29%
1	9	32%
2	9	32%
3	2	7%

This table indicates the number of clients that completed scheduled cycles. A cycle was a 10 or 12 week period for full-time Epi-Lab unit involvement and a 4 week period for the last "evaluation only" classes. It is obvious from the above table that a great majority of the clients completed at least 1 full scheduled cycle. This attests to their perseverance in maintaining their programming in the unit and at the Rehabilitation Center.

TABLE 32

COMPLETED VOCATIONAL EVALUATION

<u>Number</u>	<u>Percent</u>
7	25%

This table refers to those clients who were referred to the Center Vocational Evaluation unit and completed that program. Most of these clients were judged, as a result of full-time Epi-Lab programming, to have some vocational potential, though others, in addition to these seven, entered training without Vocational Evaluation. Of significance is that twenty-five percent of the clients improved enough in Epi-Lab to take the initial step toward vocational training. Again, completing the Vocational Evaluation program was considered to be a successful outcome for these clients irregardless of whether or not they entered vocational training afterward. Achieving entry into Vocational Evaluation attested to the motivation and perseverance of these clients in pursuing a vocational objective.

TABLE 33

ENTERED VOCATIONAL TRAINING

<u>Number</u>	<u>Percent</u>
10	36%

Ten (36%) of all clients served in Epi-Lab began another full-time training program beyond full-time Epi-Lab involvement. These training programs included Center vocational areas, sheltered workshop training, or college. All training was directed toward preparation for a specific vocational or pre-vocational goal.

TABLE 34

COMPLETED VOCATIONAL TRAINING

<u>Number</u>	<u>Percent</u>
1	4%

TABLE 35

PROGNOSIS FOR COMPLETION OF TRAINING

<u>Prognosis</u>	<u>Number</u>	<u>Percent</u>
GOOD	3	11%
POOR	2	7%

As of April 12, 1979, only one client who had entered training had completed it (Table 34). Five other clients remained in training, three with a good prognosis, two with a poor prognosis (Table 35). Those with a good prognosis were doing well in training at the end of the Project in terms of performance, motivation, attitude, or absence of behavioral problems. Those considered to have a poor prognosis were experiencing problems of poor performance, negative motivation, poor attitude, or a prominence of behavioral problems and were not expected to complete training or become employed. These judgements were made by full-time Epi-Lab staff after consulting with vocational instructors and reviewing training progress reports.

TABLE 36

CLIENTS WORKING

COMPETITIVE EMPLOYMENT

<u>Number</u>	<u>Percent</u>
1	4%

SHELTERED EMPLOYMENT

<u>Number</u>	<u>Percent</u>
1	4%

The two clients in this category were actually working in full-time employment as of April 12, 1979, and were not involved

in any full-time Project activities or Rehabilitation training programs.

TABLE 37

WITHDREW, PROGRAM NOT COMPLETED

Total

16-57%

VOLUNTARY

6-21%

INVOLUNTARY

10-36%

Clients in this category, Withdrew, Program Not Completed, did not complete the Epi-Lab program in the sense that if they had continued further benefit could have been derived by accomplishing certain critical objectives such as better seizure control, improved emotional adjustment, working toward a vocational goal or resolution of other significant problems which were considered to be barriers to attaining their maximum level of functioning.

Six (21%) withdrew for voluntary reasons that included homesickness, lack of motivation or another reason which involved the client deciding himself to discontinue programming. The ten (36%) clients who involuntarily withdrew did so for reasons such as severe medical problems precluding further programming, disciplinary-behavioral problems in which the client significantly violated Center rules and was thus terminated from the Center, disciplinary-violent behavior tendencies which rendered the client unable to adapt to the Center environment, or extreme skill or learning deficits which, after considerable programming and in the judgement of the staff, made the client unable to become a feasible candidate for further Center programming which would lead to the achievement of a vocational goal.

TABLE 38

REASONS FOR WITHDRAWAL

	<u>VOLUNTARY</u>	<u>INVOLUNTARY</u>
	<u>#</u>	<u>#</u>
<u>MEDICAL:</u>		
1. Major reason	0	2
2. Minor reason	2	1
3. Not a reason	4	7
<u>PSYCHIATRIC:</u>		
1. Major reason	1	4
2. Minor reason	4	3
3. Not a reason	1	3

DISCIPLINARY (BEHAVIOR)

1. Major reason	2	3
2. Minor reason	0	3
3. Not a reason	4	4

DISCIPLINARY (VIOLENCE)

1. Major reason	1	2
2. Minor reason	1	0
3. Not a reason	4	8

POOR MOTIVATION

1. Major reason	4	3
2. Minor reason	0	2
3. Not a reason	2	5

UNABLE TO ADAPT TO
CENTER ENVIRONMENT

1. Major reason	3	3
2. Minor reason	2	4
3. Not a reason	1	3

EXTREME SKILL DEFICIT

1. Major reason	0	1
2. Minor reason	0	3
3. Not a reason	6	6

LEARNING PROBLEMS

1. Major reason	0	1
2. Minor reason	0	3
3. Not a reason	6	6

Most clients had more than one reason for withdrawing. The preceding breakdown is cumulative and considers multiple reasons for individual client withdrawal. The staff, after reviewing documentation of the clients' withdrawal in case narratives, made some subjective judgements regarding whether one of the named reasons was major or minor. The following is a discussion of the various categories of reasons for withdrawal:

Medical: When withdrawal was considered to be for medical reasons, issues involved included discovery of malignant brain tumors, profound seizure involvement producing frequent injury, or other serious health problems. These issues were involved in the withdrawal of five clients.

Psychiatric: It is significant that psychiatric concerns were major reasons for the withdrawal of five clients. Psychiatric problems in this sense were considered to be those of sufficient severity to prognosticate that the

client would be unable to benefit from further programming because of these difficulties and would require primary psychiatric care beyond the scope of the Rehabilitation Center.

Disciplinary (Behavioral Problems): Five clients withdrew because disciplinary behavioral problems were a major factor in their situation. These problems brought the clients in conflict with Center living standards and the discipline system. Three were involuntarily terminated by the Center Administration because their behavior was not manageable and intervention attempts failed.

Disciplinary (Violent Behavior): These clients displayed actual or inclinations toward violent behavior which was disruptive to the health and welfare of themselves and other clients.

Poor Motivation-Uncooperative: Nine clients had some problem with motivation and were not willing to meet program standards by complying with the contract specifications which they agreed to.

Unable to Adapt to Center Environment: Clients in this category became homesick or were unable to achieve satisfactory social adjustment because of severe social skill deficits or their inability to live with other handicapped people. This issue was involved with five clients who voluntarily discontinued their program.

Extreme Skill Deficits: These clients were considered infeasible for further programming because of multiple problems including motor skill difficulties, cognitive deficits, coordination problems, etc. They were unable to perform even routine job-related tasks and were thus considered to have no vocational potential except for unavailable sheltered work.

Learning Problems: Four clients were involuntarily terminated because of problems in the areas of learning disabilities. Such problems as inability to comprehend or understand written or verbal directions, memory deficits and difficulty with basic academic skills were characteristic. Some were referred to the Learning Disabilities Consultant but programming proved ineffective.

TABLE 39

STATUS AT BEGINNING OF PROJECT

<u>Status</u>	<u>Number of Clients</u>	<u>Percent</u>
06-Extended Evaluation	9	32%
10-Development of IWRP	8	28%
12-Completion of IWRP	4	14%
14-Counseling & Guidance Only	2	7%
18-Training	3	11%
20-Ready for Employment	2	7%

TABLE 40

STATUS AT END OF PROJECT

<u>Status</u>	<u>Number of Clients</u>	<u>Percent</u>
06	6	21%
08-Closed from 06	1	4%
10	2	7%
12	3	11%
14	2	7%
16	1	4%
18	10	36%
22-In Employment	2	7%
24-Services Interrupted	1	4%

Note: 18 - 3 to 10 (+)movement-good outcome

Tables 34 and 40 reflect the vocational rehabilitation status information on all clients at the beginning of their program and on all clients as of April 12, 1979. It is noteworthy that many clients who had negative program outcomes were not active cases with their field counselor as of the end of the Project, even though they were not in closed status. Some had been uncooperative with the field counselor and did not respond to contact letters or did not keep appointments. Some of these cases may be closed at some future date because of the clients' uncooperativeness or because of lack of appropriate services in the field setting. Positive vocational movement of the group is evidenced by the fact that only three clients were in status 18 (training) at the beginning of the Project and ten were in this status at the close of the Project.

CLIENTS' OPINIONS REGARDING PROGRAM IMPACT:

Appendix U presents the detailed results of the questionnaire sent to all clients served in the Project following the

termination of the program on April 12, 1979. The information communicated to the program by 16 of the 28 clients served gives some indication of the impact of programming upon these individuals. Most of these clients indicated that Group Therapy and Work Area involvement were of most assistance to them in helping them to worry less about their seizures, to be more confident and understand themselves better. They strongly believed that the program was beneficial for they would recommend it to a friend with epilepsy and also strongly recommended that the Rehabilitation Center continue the program. It is noteworthy that 8 of the 16 clients recommended expanding the program to include all seizure clients at the Center rather than maintaining it as a separate unit. It is evident that they are concerned about other persons having the benefit of the experience that apparently was of benefit to them.

It is quite apparent from a brief analysis of this questionnaire that the program did accomplish its goals with many of the students in that they were able to indicate areas in which they derived benefit in responding to these questions. Of course, it must be considered that the 12 clients who did not respond are probably those that had primarily negative experiences and did not feel that benefit was derived from the program.

So, in answer to the question, "Did the Project have an impact upon clients served," it can be stated, based upon the responses of these 16 clients to the questionnaire, that a significant impact was made on some clients.

CASE HISTORIES:

Complex problems of persons with severe epilepsy are the results of the inter-relationships of many factors which are unique to each individual. Though common problems exist, idiosyncratic differences in cultural, social, educational and vocational experiences must be understood for they contribute greatly to an individual's prognosis for optimal seizure management, improved psychological functioning and vocational success.

The methods employed in the Epi-Lab program to intervene upon these problem areas become more visible when their application to individual circumstances is illustrated. Thus, the following case histories are presented as illustrations of the impact of Epi-Lab programming upon six of the clients served in the program. Each case is an example of particular issues that are common to many in this population.

Client #2 was the victim of extreme parental overprotection and environmental restriction which greatly compounded the effects of her epilepsy and other organically based problems.

Background:

Sex: Female
Age: 29

Diagnoses: Epilepsy (complex-partial)
Mental retardation (mild)

Significant Environmental Factors:

Religion: Fundamentalist

Residence: With elderly parents

Relationships: Youngest and only disabled child

Atmosphere: Overprotective and restrictive

Social interactions: Only chaperoned religious activities

Past Agency Participation: 10 years of intermittent Rehabilitation involvement

Education: GED; trained as clerk-typist and nurses' aide

Jobs Held: Clerk-typist (1 month); nurses' aide (1 week)

Client Programming in Epi-Lab:

1. Assessment:

Strengths: Good personal qualities; motivated

Deficits: Cognitive; perceptual, expressive and receptive communication problems, coordination problems, social inappropriateness, indecisiveness and severely limited personal awareness, seizures (2-3 per month consisting of screaming and incontinence).

2. Contracted Goals:

Independent living

Decision making

Appropriate behavior

Vocational skill improvement

3. Client Participated In:

Individual pre-vocational training

Occupational Therapy (activities of daily living)

Recreation - social activities, dancing, swimming, arts and crafts, plays, motor skill development activities, etc.

Counseling - using video taped role playing

Structured home assignments in independent living skills

Group Therapy

Work Area activities (prescriptive)

Epilepsy Class

Program Impact:

After almost two years of Epi-Lab involvement with this client, significant changes were observed in some areas, while little change was noted in others. On the positive side, she did receive a thorough and realistic assessment of her strengths and weaknesses

maybe for the first time. There were improvements noted in socially appropriate behavior, in self-assertion in regard to independent functioning and some improvement in decision making. After Project intervention, the home environment became less restrictive and permitted this client to assume some adult responsibilities. This woman became more socially outgoing and involved.

Problems which continued to be significant in regard to employment were learning deficits, perceptual motor functioning and coordination. Seizure frequency of 2-3 seizures per month consisting of screaming behavior and incontinence was also considered a major barrier to a successful vocational outcome. Because of these problems, this woman may never be successfully placed in competitive employment.

Current Status:

- Sheltered employment
- Traveling within the city independently
- Performing household chores
- Making independent consumer decisions
- Discussing her epilepsy with others
- Voicing personal preferences
- Arranging her own medical treatment in the community.

Client #4 illustrates the potential for normalization of life-style in spite of the almost insurmountable problems of frequent seizures and social rejection when both the timing and appropriateness of interventions is right.

Background:

- Sex: Female
- Age: 26
- Diagnosis: Epilepsy (Generalized Akinetic) Seizure frequency was 2 per day resulting in frequent injury.
- Education: High school diploma; 3 semesters at W. Va. University (resulted in academic and social failure)
- Jobs Held: None
- Significant Environmental Factors:
 - Residence: with parents
 - Atmosphere: extremely overprotective
 - Social Interactions: had maintained self-imposed isolation for 6 years.

Client Programming in Epi-Lab:

1. Assessment:

- Strengths: Average intelligence; vocational skills; potential to be attractive; language skills.

Deficits: Negative attitude (hostile, demanding, self-deprecating, critical of others); poor motivation; immaturity; poor grooming and appearance; under utilization of job skills; focus on seizures and seizure-related problems; seizure frequency (2 per day often resulting in head or body injury).

2. Contracted Goals:

Improve the use of cognitive and vocational skills
Enhance motivation
Focus away from seizures
Enhance self-acceptance
Improve ability to handle stress
Improve personal appearance

3. Client Participated In:

Group Therapy - using video taped feedback
Daily Work Area activities (given quotas and behavioral expectations)
Recreation (swimming, bowling, club activities, job in student library)
Individual counseling (emotional control, use of skills, self-concept, focusing away from seizures)
Epilepsy Class
Individual programming in clerical skill development
Job tryout in Commercial training

Program Impact:

This client's improvement as a result of participation in the Epi-Lab program was rather dramatic. Not only did her attitude, appearance and behavior change and become much more positive, but her acceptance of herself and her ability to utilize her job skills became dramatically improved. Her inter-relationships with others were less hostile and she became less preoccupied with discussing her seizures and seizure-related concerns in spite of little change in frequency of seizures.

After spending approximately 7 months in the Epi-Lab program, the client was able to enter the Center secretarial training area which she completed successfully. Following graduation, she was placed at an entry level position as a telephone solicitor with a local window company. Though she continues to experience frequent seizures and periods of deflation and anxiety, her overall ability to maintain a much more positive lifestyle is much greater than it was 2 years ago. She continues to live with her parents, as independent living is not yet practical from a financial standpoint. Living alone will probably not be advisable if frequent seizures and resultant injuries continue to recur.

Major Accomplishments:

1. Focusing away from her seizures and related issues toward the more positive aspects of her personality.
2. Less dependency upon others for emotional and financial support.
3. Utilization of innate skills and abilities in employment, daily living and leisure time activities.
4. Improvement of self-confidence to the extent that competitive employment, in spite of daily seizures, was possible.
5. Determination and courage to continue living her life in spite of daily seizures.

Client #5 is illustrative of the effects of Appalachian cultural values which stress that capacity for physical labor is equated with manhood and promote the concrete, rigid thinking pattern which restricts ability to perceive alternative solutions to problems.

Background:

Sex: Male

Age: 27

Diagnosis: Epilepsy (psychomotor type occurring sporadically following seizure-free intervals)

Significant Factors:

Occupation: Formerly a West Virginia coal miner (quit because afraid of having seizures in the mines but verbalized strongly a desire to return to the mines)

Family Situation: Wife and two small children

Attitude: Unwilling to look at vocational alternatives

Appalachian Cultural Factors: World seen as very concrete, values a man's capacity for physical labor, and having worked for a while, feels deserving of a disability check.

Jobs Held: Electrician's helper in the coal mines

Client Programming in Epi-Lab:

1. Assessment:

Strengths: Some vocational and leisure activity skills

Deficits: Negative, hostile attitude, explosive behavior, limited interpersonal skills, poor motivation, poor academic skills,

rigid and inflexible, unwilling to examine alternatives in behavior or vocational choices, focus on seizures and other somatic complaints.

2. Contracted Goals:

- Examine alternatives (in personal and vocational lifestyle)
- Reduce dependence on family support system
- Maximize neurological management
- Develop insight into emotional problems (control hostility appropriately)
- Improve social skills

3. Plan to Achieve Objectives:

- Group Therapy (deal with rigidity, hostility, emotions, getting along with others)
- Individual counseling (seek advice, clarification, examine vocational alternatives)
- Recreation (social skills, being less critical of others)
- Work Area activities (interactions with co-workers, focusing away from seizures and ailments, trying new tasks, independent behavior)

Program Impact:

This man's primary difficulty in the Project was his inability to invest himself in program goals. He continued to focus upon his seizures and his medications as the primary reason for his difficulties. He was unable to recognize and acknowledge the alternative ways of thinking which would provide him with insight into the role that his seizures were playing in his life. Significant emotional difficulties were the primary disabling condition in this case; however, one cannot discount the cultural aspects of the psychological and psychiatric opinions which made the probabilities for change so limited. This client's difficulty with impulse control, especially in regard to anger, was also a major barrier to success.

This client voluntarily left Epi-Lab without completing even one cycle of the program.

Current Status:

This man is unemployed, living with his family in a small West Virginia community. In answer to the question on the follow-up questionnaire asking for his current status, he responded, "still having spells."

Client #9 was affected not only by epilepsy, but by an associated progressively worsening severe psychiatric illness which rendered him totally incapacitated.

Background:

Sex: Male

Age: 19

Diagnosis: Epilepsy (Generalized tonic-clonic, petit mal and Kinetic types with a seizure frequency of 2 per day)

Education: High school graduate; attended art institute, expelled due to explosive angry behavior outbursts)

Significant Environmental Factors:

Psychiatric Problems: Inadequately documented psychiatric history
Inadequately documented history of explosive violent behavior

Family Status: Third of four children
Father (a minister) died 4 years ago (significant loss to client)

Social Status: Socially isolated
"Intrudes" on sibling friendships
Spends time at home doing household chores.

Client Programming in Epi-Lab:

1. Assessment:

Strengths: Vocational skills; ability to learn quickly

Deficits: Violent behavior; social inappropriateness, poor emotional expression; immaturity; uncontrolled seizures; medication side effects; negative attitude toward authority and rules; possible cognitive deficits.

2. Contracted Goals:

Maximum seizure control
Appropriate expression of feelings and concerns
Acceptance of responsibility for personal mistakes

3. Plan to Achieve Objectives:

Neurological clinic - anticonvulsant therapy
Recreation (emphasizing social interactions, appropriate behavior)

Work Area Activities

Group Therapy (self-concept, expressing feelings appropriately, controlling violent behavior, accepting responsibility for one's own behavior)

Individual Counseling (seek clarification of confusing issues, safety valve for emotions,

social skill development, learn alternative behaviors)

Epilepsy Class

Program Impact:

In October 1977, this young man entered Epi-Lab for the first time; the same month he was terminated from the Center following a violent act in which another student was injured. In September 1978, he returned to Epi-Lab after a period of counseling and psychotherapy and medical documentation that problem of violence was resolved; in October 1978 he was again terminated after assaulting a staff member.

Epi-Lab was not able to impact on this man's problems. Seizure occurrences and possible medication side effects were factors; however, severe behavioral problems, manifested in an explosive aggressive style of behavior, were the primary difficulty. A chronic pattern of physical attacks directed at others was in evidence. This type of behavior was beyond the tolerance level or therapeutic capabilities of the Rehabilitation Center. Despite the fact that this is a truly severely disabled person, his retention at the Rehabilitation Center was not considered to be in the best interests of other students or staff at the facility.

Current Status:

This man is now confined to a mental institution. The prognosis for recovery and a positive outcome is not known. However, overcoming the stigma of epilepsy, the stigma of mental illness, the loss of many positive interpersonal relationships, and possible diminished self-esteem make the prospects for complete recovery and a positive outcome look slim.

Client #14 was unable to develop her exceptional vocational potential or adjust to her disability because of a chronic severe personality disorder which was not responsive to treatment.

Background:

Sex: Female

Age: 25

Marital Status: Divorced

Diagnosis: Epilepsy (Generalized tonic-clonic, petit mal and psychomotor types)

Education: High school graduate

Significant Factors:

Emotional History: Secondary disability of hysterical personality; received psychiatric treatment at Behavioral Medicine; history of emotional problems.

Family Status: Has one child living with ex-husband
Client was allegedly an abused child

Client lives with mother and siblings

Focus of Attention: Seizures and numerous other questionable ailments (colitis, back problems, rashes, gallbladder, chest pains, and others).

Behavior and Attitude: Hostile, aggressive, manipulative, demanding, explosive, but sometimes fluctuated to a facade of demureness, excessive warmth and mirth.

Interpersonal Relationships: Appears to alienate family, co-workers, peers and staff alike

Client Programming in Epi-Lab:

1. Assessment:

Strengths: Strong vocational skills, good functional academic skills, above average verbal communication skills.

Deficits: Negative attitude, hostile and manipulative behavior, poor interpersonal skills, inappropriate social adjustment, focus on seizures and other medical complaints, slightly limited math skills

2. Program Goals:

Better emotional control
More positive attitude
Focusing away from seizures and ailments
Consistent positive behavior
Seizure control
Accepting constructive criticism, feedback and supervision appropriately
Improved interpersonal relationships

3. Client Participated In:

Group Therapy - emphasis on attitude, behavior, interpersonal relationships

Individual Counseling - examining vocational alternatives, emotional control, motivation, attitude and behavior

Recreation - social interactions, attitude

Remedial Education - to improve math skills

Work Area Activities - interpersonal relationships, focusing on positives, attitude, behavior, emotional stability as related to vocational potential.

Vocational Evaluation - successfully completed

Training Tryout - successfully completed

Program Impact:

This client possessed above average vocational skills and the intelligence to complete her chosen vocational training. However, her medical complaints, behavioral and emotional problems represented significant barriers to her chances for vocational success. Furthermore, this woman's deficient interpersonal skills were another major liability. Epi-Lab was not able to successfully impact on this woman's problems in any substantial way due to her inconsistent levels of program involvement and commitment to goals. Moreover, due to the chronic nature of her emotional difficulties, one must question this client's ability to benefit from further Project intervention.

Current Status:

This client is in a vocational training area at the Rehabilitation Center. However, the prognosis for successful completion and eventual job placement is not good due to the same medical, behavioral, attitudinal and emotional problems that limited her success in Epi-Lab.

Client #15, in spite of many positive attributes which pointed to a very favorable prognosis, was unable to overcome the personal defeat and frustration of epilepsy-related negative experiences because of rigid thinking and strong masculine role expectations that were probably culturally induced.

Background:

Sex: Male

Age: 23

Diagnosis: Epilepsy (Generalized tonic-clonic and psychomotor type with a frequency of 1 per week)

Education: High school graduate

Significant Factors:

Residence: Lived with parents and disabled brother in a Southern West Virginia coal mining community

Appalachian Cultural Values: Reared by his father and grandfather to believe that a man is his work; employment equals independence; respect your elders; a man acts on his beliefs; be the best there is at everything you do.

Social Outlet: None

Jobs Held: Machinist, handyman

Client Programming in Epi-Lab:

1. Assessment:

Strengths: Personable, appearance and grooming

excellent, vocational skills, average intelligence

Deficits: Rigidity in expectations of others; perseveration on past experiences, poor receptive communication skills, quick temper, lack of insight, focus on seizures as reason for vocational failures, poor academic functioning, coordination problems, extremely slow work rate.

2. Contracted Goals:

Emotional control of violent behavior and quick temper
Promote positive self-image (understand and accept deficits)
Accept epilepsy, become more confident
Focus on future not the past
Improve skills (increase work rate, eliminate compulsion for perfection)
Explore job alternatives
Try not to get so upset with others (listen)

3. Client Participated in:

Group Therapy - emotional control, self-concept, expectations of others
Recreation - drama, pool, arts and crafts
Individual Counseling - future orientation, self-image, interpersonal relationships
Epilepsy Class
Vocational Evaluation
Remedial Education

Program Impact:

Testing and observation indicated this man had vocational skills, however, major attitudinal and behavioral deficits prevented the client from gaining maximum benefit from Project services or making substantial improvement in his vocational or personal situation. It is believed that many of this client's behavioral problems stemmed from his rigid expectations of other people based on dogmented cultural beliefs. Unfortunately, the client did not, during his participation in Epi-Lab, possess the flexibility in thinking to examine alternative ideas and circumstances and, therefore, found his situation intolerable.

His situation was aggravated by a perseveration on negative past employment experiences. The client's deflated self-image was highly related to his perceived inability to be accepted in a work situation because of his epilepsy. The resulting bitterness and anger over this rejection interfered in his ability to utilize present opportunities.

Current Status:

Living at home with his parents; is unemployed.

STAFF OPINIONS REGARDING PROGRAM IMPACT:

Appendix V contains a detailed analysis of a questionnaire sent to selected staff for the purpose of eliciting feedback from Agency staff in regard to the program impact in various areas. A brief survey of the responses to this questionnaire indicates that the program impact was felt during the Project period by staff at the Center, as well as in the field. Some of the highlights of the results of this questionnaire are as follows:

1. The program had some impact upon all staff in their work with epilepsy from a client-serving, administrative, or management standpoint.
2. Those that were in a position to be aware of client change believed that change did occur in those clients served by Epi-Lab. Most staff felt that the areas in which change occurred were in "improvement of behavior," "independence," "social and interpersonal skills," and "coping ability."
3. In the opinion of most staff, Epi-Lab should be continued by incorporating the successful parts of the program into other existing Center programs. It is significant that only five percent of the staff did not recommend continuation of the Project in some form.

Of course, all opinions were not positive and many constructive criticisms and suggestions were made by the staff in response to the questionnaire (See Appendix V). However, it must be concluded on the basis of the questionnaire responses, that in the opinion of those staff members who answered the questionnaire, the impact of the Epilepsy Project was felt strongly within the Rehabilitation Agency at all levels. If the result of this impact is a positive change in the effectiveness of service delivery to the population of severely disabled epileptics, then one of the major goals of the Project will have been accomplished. However, information in regard to this important result will be available only in the years to come.

CHAPTER VII

OVERALL ACCOMPLISHMENTS

All sections of this detailed report contain discussions of certain accomplishments of the Project in specific program areas. However, major accomplishments warrant separate discussion, for they describe the degree to which the primary purposes for establishing the Project were fulfilled.

1. The first of these involves the acquisition of new knowledge pertinent to the vocational rehabilitation of people with severe epilepsy. Several insights, resulting from Project activities, deserve note. The opinion that seizure frequency alone was not the reason for failure of these clients was confirmed. Intensive work with small numbers of clients enabled a greater understanding of the problems of behavioral maladjustment, learning disabilities, communication deficits, recreational deficiencies, etc., which combine to make successful lifestyle adjustment difficult for these people. This knowledge should help to make Vocational Rehabilitation programming in the future more pertinent, especially programming for clients at the West Virginia Rehabilitation Center.
2. In regard to the behavioral problems, it is significant that the observations of clients in the Project indicate that the ability to live with epilepsy does not depend entirely upon seizure control. Some of the clients themselves in personal testimony (See Forward, page iii) and in response to the client questionnaire (See Appendix V) attest to the fact that if assistance is given in the area of learning new ways of perceiving their lives and dealing with problems, overall lifestyle can be improved, change can take place, and persons who had resigned themselves to lives of dependency and non-productivity can be more independent and more productive.
3. The advantages of a multi-disciplinary team effort were acknowledged by all professionals involved in the Project. The contribution by each discipline was enhanced by knowledge of the activities of other staff working with a particular client. Though improvements in communication and working relationships could be made, the Project demonstrated the desirability of working as a team toward this goal.
4. The role of Vocational Rehabilitation in the overall care and management of the epileptic client was clarified, especially in regard to the role of the Vocational Rehabilitation Center. Seizure control should not be a prerequisite for Vocational Rehabilitation involvement, but rather, Vocational Rehabilitation should function

to coordinate, not necessarily provide, all services, medical, psychological, vocational, etc., that are necessary to evaluate and treat the client so that his potential for total lifestyle improvement can be maximized.

5. The value of a controlled, concentrated, work activity setting in providing a thorough evaluation of the multiple problems of these people was demonstrated by Epi-Lab. This unique unit, which utilized some of the components of a sheltered workshop, a work evaluation unit, a therapy unit, and an educational classroom, has proven to be a great advantage in gaining a full understanding of the client and his potentials as they involve the varying conditions accompanying his epilepsy.
6. A workable model for the intensive evaluation of and Rehabilitation programming for the severely disabled epileptic client resulted from the first two years of client programming. The Transition Model (See pages 86 through 91) utilizes the advantages of the multidisciplinary approach and avoids the pitfalls of an isolated segregated unit, while maximizing the impact of programming upon the critical areas of need in this population.
7. Development of materials and tools was one of the original objectives of the Project and in this area two accomplishments are significant.

One was the Epi-Lab Performance Summary (See Appendix M) which greatly assisted in the comprehensive evaluation of the vocationally significant behaviors of the clients.

The second was the Epilepsy Class Curriculum (See Epilepsy Class description, page 60; and Appendix S), which is considered to be a comprehensive listing of information and topics that should be considered in any comprehensive programming with people with epilepsy.

8. A greater understanding of the process involved in planning and implementing a program of this type was aided by attending to the details of the process (See Program Process section, pages 13 through 35). It is believed that attention to the process of programming uncovered significant information regarding the reasons for success or failure of program components. This awareness of problems is critical to the effectiveness of future efforts and can help others who would seek to duplicate such a program avoid the pitfalls of making the same errors in program development.
9. As a result of this Project's location at the West

Virginia Rehabilitation Center and its efforts in staff training, several breakthroughs were made in the areas of

- a. staff knowledge of epilepsy, its treatment and other problems these clients experience (especially behavioral problems),
 - b. attitudes of staff toward the uncontrolled epileptic,
 - c. the staffs' ability to appropriately handle seizure episodes and maladaptive behavior, and
 - d. improved medical treatment in terms of having the capacity to utilize frequent blood level determinations, having access to the EMIT system and also the improved attitudes and procedures that are now present within the Center.
10. The Project had several opportunities to have an impact upon public knowledge and attitudes. By co-sponsoring various conferences with the Mountain State Epilepsy League and the Developmental Disabilities Council, Epi-Lab helped to bring needed information to nurses, welfare workers, health professionals, rehabilitation personnel and consumers.

CHAPTER VIII

RECOMMENDATIONS

The preceding comprehensive report of all program areas of Epi-Lab contains specific recommendations relative to particular aspects of the program. However, an overall evaluation of the Project points out several major issues which must be included as primary recommendations based upon knowledge gained in the Project. The recommendations can be discussed in three categories:

1. those for the Rehabilitation Center specifically,
2. those pertinent to the Rehabilitation Agency as a whole, and
3. those of concern to other persons and agencies providing services to people with epilepsy.

RECOMMENDATIONS FOR WEST VIRGINIA REHABILITATION CENTER:

1. If the Project is not continued in its present form, the Rehabilitation Center Administration should appoint a coordinator of epilepsy services for the Center. This person, who must possess a special knowledge of the problems of the person with epilepsy, would teach epilepsy classes, counsel epileptic clients on special problems, coordinate multi-disciplinary services that are necessary to thoroughly evaluate and serve these clients, and make the Administration aware of staff training needs. This position could be filled on a part-time basis and could greatly enhance services to epileptic clients if the necessary staff support is provided.
2. Special programming for all clients with epilepsy should continue at the Rehabilitation Center utilizing the Transition Model (See pages 86 through 91) as a guide. Special programming directed toward unique needs of people with epilepsy must be incorporated into vocational programming if maximum chances for success are to be realized.
3. The problem of learning disabilities in this population and with other persons at the Rehabilitation Center needs further investigation. It is believed that the Epilepsy Project has established the existence of this problem and suggested several ways of possibly intervening or more thoroughly investigating this area (See Learning Disabilities section, pages 75 through 86). The Epilepsy Project has established the severity of these learning difficulties in persons with even mild organic

brain involvement. For many of these persons progress in any new life endeavor, vocational training, counseling, or interpersonal relationships, will depend upon the finding of solutions to these learning difficulties.

4. Programming directed toward resolving the behavioral problems of people such as those served in the Project should be continued. Group therapy and group counseling were effective in Epi-Lab, in that they provided a structured opportunity, central to their program, for clients to learn to recognize and correct maladaptive behaviors which were self-defeating and were barriers to personal and vocational growth. The value and practicality of providing this type of programming for all Center clients should be investigated.
5. An increased time commitment and an expanded role for the neurological consultant would help to facilitate provision of comprehensive medical treatment to clients with epilepsy at the Rehabilitation Center. Additionally, the clinic nurse job description should be expanded to include specific assignments relative to the needs of epileptic clients. This would include detailed charting of seizure activity and medication compliance; coordination of supportive medical services such as blood level determination, prescription changes, and frequency of neurological visits; and coordination of communication between the staff and the neurologist.
6. The intensive evaluation of the multiple problems of people with epilepsy that was carried out in the Epi-Lab unit should be continued in Work Evaluation or the Sheltered Workshop if a complete understanding and realistic assessment of these clients is to be made.
7. The contributions made by the Recreation department in assisting clients in problem areas of personal behavior, socialization, leisure time utilization, etc., should continue to receive emphasis. Prescribed recreation for some clients helped to overcome the effects of dependency and severe restriction. Counseling towards these types of goals is not sufficient, for often experimentation by the client in activities that were previously forbidden contributes to increased self-esteem and self-confidence which leads to more independent functioning.
8. Services such as group therapy, epilepsy class, special counseling, etc., must be made mandatory for clients and given equal emphasis to vocational programs if they are to be effective. It has been learned in Epi-Lab that, in many cases, the behavioral problems and lack of competent adaptive skills are much more significant in vocational outcome than a lack of specific job skills.
9. Ongoing training of all Center staff in the comprehensive

management of persons with epilepsy should be a goal of the Center Staff Development unit. Periodic workshops and other training devices can help to maintain the positive strides made in staff development during the Project period.

RECOMMENDATIONS TO WEST VIRGINIA DIVISION OF VOCATIONAL REHABILITATION:

1. More sheltered work opportunities are needed for clients who have the more severe skill and learning deficits, as well as uncontrollable seizures. Many clients served in Epi-Lab do not have potential for competitive employment. However, some gainful activity could be possible in a sheltered setting. For many of these clients sheltered workshops are not available in their communities. This problem, which is common to other disability groups, is also critical for people with epilepsy.
2. Vocational Rehabilitation programming should be directed toward goals beyond vocational placement. The Agency must recognize the unique capabilities of the Rehabilitation Center in dealing in a multi-disciplinary fashion with the unique problems of this disability group. Many services that these persons need are not available in the home communities in the rural State of West Virginia. This is especially true in regard to independent living programs. They need to learn how to live independently and capably before work concerns are addressed. The development of competent and capable persons should be a goal of equal importance to job placement.
3. Rehabilitation's role in case finding and coordination of medical and behavioral services needs to be continued. The field program must recognize the lengthy process involved in rehabilitating a person with severe epilepsy and be prepared to coordinate services of other agencies such as the Department of Welfare, Department of Mental Health, and the Division of Crippled Children's Services which can establish seizure control, improve behavioral functioning and develop independent living skills prior to vocational intervention by Rehabilitation. Vocational goals of these people can only be met if other agencies are successful in these other areas.
4. Job placement efforts in the field and in the Center must consider the fact that many of these severely disabled epileptic clients cannot perform all tasks involved in most competitive jobs. However, some excel in specific activities which could be accomplished if job modification and on-the-job training were utilized.
5. Many job placements of these people will depend upon the Agency's ability to persuade employers to modify jobs to accommodate epileptic clients with learning and skill deficits in certain areas. The enormity of this task is

recognized, but an attempt should be made to accomplish it if many of these people are to obtain gainful employment.

6. In order to work more effectively with severely disabled epileptic clients, more medical, psychological, and social information needs to be at the disposal of the field counselor. Often the information contained in the cases submitted to the Epilepsy Project was inadequate for Rehabilitation purposes. Neurological reports should contain information regarding seizure frequency, type, manifestation of seizure behavior, behavioral problems, etc. Of course, the physician is often unaware and does not have access to some information that would be most helpful to a Rehabilitation counselor. This points to the value of having a unit such as Epi-Lab available in which to thoroughly evaluate the multi-faceted difficulties that these people experience.
7. It is important to the rehabilitation of any epileptic client that Rehabilitation personnel look beyond the seizures. While seizure control is important, it is equally important that other issues such as learning difficulties and behavioral problems be addressed and understood as they apply to the individual case. If a client with epilepsy is successful in maximizing his potential, he must change his focus away from his seizures and toward the more positive assets and abilities. By the same token, any helping professional who focuses upon the person's seizure activity alone is limited in his capacity to be of assistance. When the seizures are de-emphasized, often they become less important, and as improvements are realized in other areas, the seizures decrease in importance even further. This is true even if the actual frequency remains constant. As the impact of epilepsy upon the person's personal and vocational functioning is decreased, goals such as self-esteem, independent living, working and successful interpersonal relations that seemed unattainable, become realistic.

RECOMMENDATIONS FOR OTHER AGENCIES WORKING WITH PEOPLE WITH EPILEPSY:

1. The total rehabilitation of the person with epilepsy is beyond the capability of any one agency such as Vocational Rehabilitation. Community services are critical in providing follow-up and meeting the medical and behavioral needs of epileptic clients. The role of the Department of Health, the Department of Mental Health, the Department of Welfare and Education is critical in the areas of family education, patient education, counseling, psychotherapy, etc. The services of these other agencies must be much broader in scope and include services beyond mere seizure control clinics.

2. Family counseling from childhood would be of great assistance in preventing many of the behavioral difficulties that the Epi-Lab clients experienced as adults. Attitudes and concepts that these clients form about themselves are major motivating factors in adult life. Family support of positive concepts of self is crucial. Vocational efforts cannot be successful unless these types of issues can be successfully resolved. The family can certainly undermine positive gains made in other program areas.
3. Training needs of teachers, nurses, institutional personnel, Vocational Rehabilitation personnel, Welfare workers, etc., were recognized during the Project period. Many of these other agencies recognize deficit areas and are seeking appropriate training which is practically non-existent in West Virginia. Specific avenues for resolution of this problem are not known at the present time. However, a more viable State epilepsy consumer group would certainly be a facilitator of such efforts.

CHAPTER IX

PLANS FOR CONTINUATION

The Epilepsy Project has provided the West Virginia Rehabilitation Center with an opportunity to examine, in depth, some new ideas and different methods of programming directed toward rehabilitation of severely disabled people with epilepsy. The purpose was not necessarily to establish a program which would continue as a separate entity after the expiration of the Grant, rather the primary intention was to gain new knowledge. The Project staff did not recommend a continuation of Epi-Lab as an individual entity, but rather, suggested that an assimilation of the successful ideas of Epi-Lab into the existing Rehabilitation Center program would be the most appropriate method of continuing Project services.

The staff of the Agency Program Planning Section and the Administrative staff of the Rehabilitation Center will scrutinize the recommendations of the Project and closely assess desirability and feasibility of incorporating these recommendations into the existing Center programs in which epileptic clients participate. Of particular importance is the question of the feasibility of continuing the portions of the Project that addressed the maladaptive behavior problems of these clients. To incorporate this aspect of Epi-Lab into the existing structure of the Center vocational program would require significant changes in philosophy and operation of existing programs. The feasibility and desirability of such a modification will be determined in the months to come.

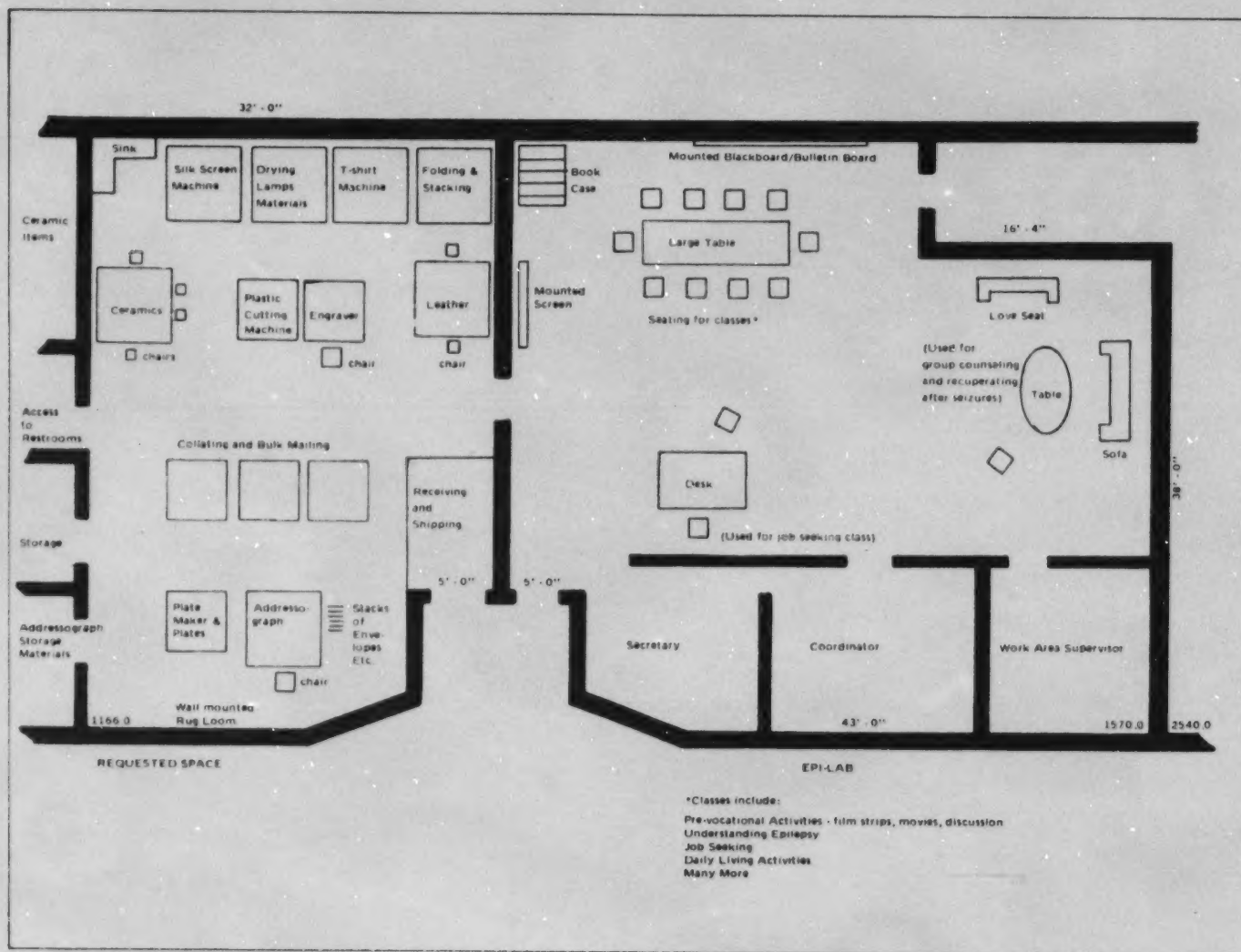
The Agency will also seek to widely distribute the Project results and accomplishments to all Rehabilitation Agency client serving staff and other agencies serving people with epilepsy so that the knowledge gained will have benefit for all.

Also, during the Project, extensive data was collected, particularly psychometric data which could not be analyzed for use in this report because of technical and personnel difficulties. However, the Agency and the West Virginia Rehabilitation Research and Training Center will maintain this information, utilize it in future planning and, hopefully, report any significant findings in the professional literature.

Epi-Lab has certainly made an impact upon many people concerned with the problems of epilepsy throughout the State of West Virginia. The ultimate accomplishment will be a continuation of the momentum that the program has begun by continuing to build upon the foundation of Epi-Lab. The Vocational Rehabilitation Agency, in fulfilling its commitment to provide the best possible services to clients with severe disabilities such as epilepsy, will certainly utilize the knowledge of Epi-Lab to perpetuate the improvements that have been made.

EPI-LAB FLOOR PLAN

A-1



APPENDIX A

APPENDIX B

EPILEPSY REHABILITATION - THE EPI-LAB APPROACH

April 12, 1977

8:45 a.m.	Welcome	George F. Gay
	Opening Remarks	Earl W. Wolfe
9:00 a.m.	New Federal and State Guidelines Regarding Vocational Rehabilitation of the Severely Disabled	Bill F. Gardner
9:15 a.m.	Introduction to WVRC Epilepsy Project	William R. Phelps David K. Steurer
9:45 a.m.	Break	
10:00 a.m.	Epilepsy: A Historical Perspective	Curtis L. Withrow, M.D.
10:30 a.m.	Behavioral Considerations	Pinckney McIlwain, M.D.
11:00 a.m.	Psycho-Social Aspects	David A. Clayman, Ph.D
11:30 a.m.	Questions and Answers	
12:00 p.m.	Lunch	
1:00 p.m.	Small Groups	
	Group I - Medical Aspects - Dr. Withrow - Auditorium	
	Group II - Vocational Aspects - Dr. McCoy - Bowling Alley	
	Group III - Psychological Aspects - Dr. McIlwain - Client Library	
	Group IV - Psychological Aspects - Dr. Clayman - Creative Arts	
2:15 p.m.	Break	
2:30 p.m.	Small Groups	
	Group I - Psychological Aspects - Dr. McIlwain - Client Library	
	Group II - Psychological Aspects - Dr. Clayman - Creative Arts	
	Group III - Medical Aspects - Dr. Withrow - Auditorium	
	Group IV - Vocational Aspects - Dr. McCoy - Bowling Alley	
3:45 p.m.	Open House - Epi-Lab	

APPENDIX C

PROGRAMS PRESENTED BY EPI-LAB STAFF

The following programs, with the approximate number of persons in attendance, were presented by various staff of Epi-Lab for different purposes:

October 1977

Project Coordinator visited Division of Crippled Children's Seizure Clinic to talk with parents and inform staff of Epi-Lab services. 25

February 1978

Project Coordinator, Work Area Supervisor, and one client presented a workshop in an Affirmative Action seminar for college personnel directors and deans. The program consisted of a video tape presentation regarding the employment concerns of people with seizures, followed by the Project client discussing with the group her perceptions of life with seizures. 20

March 1978

The Secretary/Case-Aide and the Division of Vocational Rehabilitation Medical Director presented a program on epilepsy to the West Virginia Rehabilitation Association-Pilot Club Conference. Mrs. Mullins, through a role-play situation with Dr. McCoy, conveyed in a very personal manner the perceptions of life as experienced by a person with seizures. The Pilot Club, a civic organization, was targeting convulsive disorders as an area of major concern during that year. Thus, the Project was able to have an impact upon this group by increasing their awareness of the problems of people with seizures. 50

The Project Coordinator attended a meeting of the Mountain State Epilepsy League and presented a program about Epi-Lab, thus informing the West Virginia consumer group about this new service for persons with seizures in West Virginia. 30

April 1978

Project Coordinator presented a workshop for the 18

Center horticulture training class in which there were ten epileptic students. Accomplishments included the discussion of some of the fears and anxieties of class members, instruction in proper handling of seizures, and conveying of general information which proved to be of a helpful nature.

The Project Coordinator presented a program on Epi-Lab, its philosophy and intervention methodology to a group of nursing students. 40

May 1978

The Project Coordinator visited three of the larger districts in the Rehabilitation Agency presenting the slide show, distributing brochures, and reviewing cases. Issues of general concern to the Rehabilitation counselor in serving the epileptic client were discussed. 75

The Project Coordinator presented a program to nursing students. 20

June 1978

Epi-Lab psychiatric consultant, Dr. McIlwain, presented a paper (which was awarded first place) to Charleston Area Medical Center physicians on Medical Education Day. In his presentation Dr. McIlwain discussed the Epi-Lab approach to the psychosocial management of seizure disorders and illustrated his presentation with a video tape and case study of one of the Epi-Lab students. As a result of this presentation, many contacts were made with the medical community which were heretofore not forthcoming. Dr. McIlwain, through his presentation, increased the awareness of Epi-Lab in the local medical community. 250

July 1978

The Project Secretary/Case-Aide and the Agency Medical Director presented a program to the National Pilot Club in Washington, D.C. This invitation was the result of the highly acclaimed effort of Mrs. Mullins and Dr. McCoy in March 1978 at the local State Conference. This national involvement of one of our staff members attests to the multiple talents which were utilized beyond actual job performance in making a contribution to 150

persons with epilepsy.

August 1978

Project Work Area Supervisor, Mrs. Davidson, presented a program to new Agency staff regarding epilepsy in general and Epi-Lab in particular.

10

The Agency Staff Development unit utilized some of the Epi-Lab educational materials in a secretary's orientation at the State Rehabilitation Conference.

APPENDIX D

DIVISION OF VOCATIONAL REHABILITATION
State Capitol Building
Charleston, West Virginia 25305

DIRECTOR'S LETTER 77-6

February 9, 1977

SUBJECT: Selection and Referral of Cases to Center Epilepsy Project

1. Background. The agency initiated on November 1, 1976, an innovation and expansion project at the West Virginia Rehabilitation Center entitled "Vocational Rehabilitation of Persons with Poorly Controlled Epileptic Seizures." David Steurer is the counselor-coordinator, while other full-time staff are Ethel Davidson, work area supervisor, and Shirley Mullins, secretary-case aide. Part-time staff consists of Curtis Withrow, M.D., neurological consultant; Pickney McIlwain, M.D., psychiatric consultant; and David Clayman, Ph. D., psychological consultant.

2. Purpose. This letter informs staff of the purposes and methodology of the project, and provides guidance on selection and referral of clients.

3. Project Purpose and Methodology. The project is intended to rehabilitate those clients who experience frequent epileptic seizures and have chronic seizure-related problems of poor self-image, limited work background, limited schooling, and maladaptive behavior such as prolonged withdrawal and isolation.

a. The project will provide five major types of rehabilitation services: seizure control, evaluation of rehabilitation potential, work conditioning, vocational training, and personal adjustment and education.

b. The project will have a vocational emphasis, but attention will be directed toward the medical and psychological dynamics of the client's seizure disorder. Seizure control and behavior change and adjustment to work will be primary goals for each client.

c. Clients will spend the majority of their time in the "Epi-Lab," a work area where they will perform contract work under close supervision. However, they will also be exposed to group counseling, group discussions, recreational activities (both structured and unstructured), educational experiences, and other Center services as deemed necessary. Emphasis in the work activities will be on intensive evaluation and preparation of the client for future vocational training and placement.

4. Identification of Prospective Clients. Among clients who may be suitable prospects for the project are:

a. Clients who have received conventional rehabilitation services, but who continue to be unemployable because of their seizures (some may have been closed in Status 08, 28, or 30, while others may still be in the active caseload with little or no progress being made toward achieving a vocational

goal);

b. Clients who have been excluded for Center admission or who were previously enrolled at the Center but were unsuccessful in completing the program there;

c. Clients who are unemployed or underemployed because of the severity of their seizures and related problems; and,

d. New referrals from neurologists and other physicians, Department of Welfare Crippled Children's Division, schools, Social Security Administration, and the Department of Mental Health.

5. Referral to Project.

a. Calender. Clients will be served on a class basis in the project, with the first class scheduled to begin April 17, 1977, and run for a three or four month duration. Subsequent classes may run longer or shorter, depending on experience with the initial class.

(1) Referrals for the first class must be submitted not later than March 22, 1977.

(2) Clients selected for the first class and their counselors will be notified by March 29, 1977. Appropriate instructions regarding clients not selected will be issued by the project staff.

b. Required Information. The entire case folder will be submitted under cover of a memorandum to the Center Registrar, requesting that the client be considered for the epilepsy project. The case folder must include as a minimum, the following:

(1) A medical report of the diagnosis of epilepsy, code 630.

(2) A treatment history, including records of previous hospitalization, psychiatric/neurological examinations, psychological evaluations, and records of medication prescribed and used.

(3) Present medical regime, if applicable, and medication prescribed.

(4) A summary by the counselor to include:

(a) The problems encountered by the client in educational, work, and family settings;

(b) Evidence of behavior problems such as withdrawal, aggression, or manipulation of environment;

(c) Previous efforts, if any, of the agency or other agencies to help the client resolve his problems;

(d) Current physician, if any, following the client;

(e) Current descriptive information relating to the frequency of attacks, descriptions of the seizure episodes, consequences of the seizures, age at onset, and related information; and,

(f) Statements of other disabling conditions.

c. Desired Information. If available, EEG's and skull x-rays should be included in the case folder, as well as medical reports of other neurological conditions or deficits.

6. Preparation of Individualized Written Rehabilitation Program. The following instructions govern preparation of the Individualized Written Rehabilitation Program (IWRP) for each client selected.

a. If the client is in Status 00 or 02 when selected, the field counselor will complete the preliminary diagnostic study.

(1) If found eligible for rehabilitation services, the case will be moved into Status 10 and the initial IWRP developed. The client will enter the project in Status 10.

(2) If found acceptable for extended evaluation, the case will be kept in Status 02 by the field counselor. The initial IWRP will be developed while in that status. Once the client has begun project services, the project staff will move the case into Status 06.

b. If the client already is in Status 06 when selected, the field counselor will amend the IWRP if necessary, spelling out the services to be provided in the project. In most cases, WVDVR-90 will require an amendment to show the client enrolled in the project, while WVDVR-90C will require a listing of the major project services to be provided, as listed previously in this letter.

c. If the client is in Status 10 or higher, the field counselor will prepare the IWRP, or amend it as necessary, entering details of the project and the services to be provided.

d. If the client is receiving post-employment services in Status 32, he may not enter the project in that status, as the project entails a new range of services not related to the original rehabilitation effort. Therefore, the client must be closed from post-employment services and the case reopened.

e. As with the IWRP for any client going to the Center, the field counselor must include incidental maintenance, if the client qualifies under economic need. Also, transportation to and from the Center must be included.

7. Client Preparation. To assure success while in the project, the client must be made thoroughly familiar with the purposes and methodology of the project. The field counselor should do that in his discussion with the client, both at the time the client is proposed for admission and later when the client has been selected. The client should be made cognizant of the vocational emphasis of the project, as well as with the medical and psychological aspects. The project staff will be available to assist in client preparation and should be consulted as necessary. Whenever possible, tours of the

Center and pre-admission conferences are recommended.

8. Questions. Questions should be addressed to Mr. Steurer or to William R. Phelps, Chief, Research and Development.

Thorold S. Funk, Director

Attachment: None

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APPENDIX E

West Virginia

Division of Vocational Rehabilitation

STAFF BULLETIN

Charleston, West Virginia • October 4, 1976

EPILEPSY PROJECT INITIATED

A new innovation and expansion project to serve persons with epilepsy has been approved. The title of the project is "Vocational Rehabilitation of Persons with Poorly Controlled Epileptic Seizures." The project will begin on or shortly after October 1.

Under the project, a special program for epileptics will be established at the West Virginia Rehabilitation Center. The program is designed to serve persons who have received conventional treatment but who continue to be unemployable because of seizures. In the program at the Center, emphasis will be on improving control of seizures, evaluation of rehabilitation potential, and vocational adjustment. The program will seek to improve control of seizures by milieu therapy involving a combination of medical, psychological, social, recreational, and vocational services. The program will include an "Epi-Lab" in which the clients will engage in actual work activities. The project is designed to assist field counselors in rehabilitating the severely disabled by providing a new resource.

The staff of the project will include three full-time positions and three part-time positions. The full-time positions are counselor-coordinator, work area supervisor, and secretary-case aide. The part-time positions are neurologist, psychiatrist, and psychologist. The central Personnel Office is now accepting applications for employment in the project.

West Virginia

Division of Vocational Rehabilitation

STAFF BULLETIN

Charleston, West Virginia • December 13, 1976

PROGRESS REPORT ON EPILEPSY PROJECT

The new I & E Epilepsy Project at the West Virginia Rehabilitation Center began officially on November 1, 1976, with the appointment of David Steurer as Project Coordinator. Shirley Mullins, formerly a secretary in the Center Medical Section, has been appointed as Secretary/Case Aide to the project. Other position vacancies have yet to be filled.

The essential organizational matters of physical space, curriculum development, work activity development, and staff training have occupied the first month. A portion of the old recreation complex has been allotted to the project for use as office space and the epilepsy laboratory (Epi-Lab). Modification of the area is currently underway with completion expected prior to January 1. Many items of equipment and furniture have been ordered, and hopefully the staff will be able to occupy the facility in the near future.

While awaiting completion of the physical facility, the staff will concentrate upon curriculum development and training. Plans for securing contract work and developing crafts activities have been initiated and will be finalized by the Work Area Supervisor. In addition to reviewing the literature in epilepsy rehabilitation, the staff is hoping to enhance their knowledge and ideas by visiting several other facilities which have exemplary programs. These include Epi-Hab, Inc., Evansville, Indiana; Comprehensive Epilepsy Program, University of Virginia, Charlottesville; and Colin Anderson Center, St. Marys. It is expected that much of the initial program direction will be a result of ideas that others are utilizing successfully.

A Director's Letter setting forth client selection criteria and specifics of program content will be forthcoming shortly. In the interim, field counselors are encouraged to begin reviewing their caseloads for persons, male or female, of working age who are experiencing frequent seizures and severe seizure-related problems. Clients sought may be those who were not previously considered as acceptable for Center services. Some may have been previously closed in Status 08.

APPENDIX F

Medical Center
Charleston Division

P.O. Box 2867
1210 Elmwood Avenue
Charleston, WV 25330

Department of
Behavioral Medicine
and Psychiatry

**West Virginia
University**

Dear Dr.

I am writing to ask for your assistance and support in behalf of the Epi-Lab Project sponsored by the West Virginia Division of Vocational Rehabilitation. This Project, funded through a Federal Innovation and Expansion Grant, is intended to explore new territories in the rehabilitation of those individuals who have uncontrolled seizures and, as a result, have not previously been eligible for services through DVR. Our aim is to provide an interdisciplinary approach to a very complex problem. The major problem we face at the present time is the lack of an adequate pool of applicants from which to select new clients. Our major selection criteria are:

1. Uncontrolled seizure disorder
2. IQ greater than 80
3. Have reached the age of majority
4. Have no other major disabilities
5. Are willing to reside at the West Virginia Rehabilitation Center in Institute, West Virginia during the period of participation (with the exception of standard weekend and holiday leaves.)

As implied by the title of the grant funding this Project, our approach and philosophy are somewhat novel. Let me assure you, however, that even though our "game plan" is an experimental one, our ultimate goal is to benefit the individual participant. To my understanding, we have the rare opportunity to explore new avenues in assessment and treatment approaches without the constraints of usual barriers.

Page Two

Perhaps you have among your patient population an individual for whom you think our program would be appropriate. We would certainly appreciate the opportunity to review whatever information you have available and discuss the program with you and your patient. Should you have a potential client or simply desire more information, please feel free to contact Mr. David Steurer, Epi-Lab Director, at the West Virginia Rehabilitation Center, Institute, West Virginia, phone number 768-8861, or me, Pinckney McIlwain, M. D., Department of Behavioral Medicine, Charleston Division, West Virginia University Medical Center, Charleston, West Virginia, phone 348-7695.

Thank you for your time and consideration.

Respectfully,

Pinckney McIlwain, M. D.
Psychiatric Consultant, Epi-Lab Project
and Resident in Psychiatry
Department of Behavioral Medicine
Charleston Division
W. Va. University Medical Center

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APPENDIX G

EPI-LAB ARTICLE IN
THE WEST VIRGINIA MEDICAL JOURNAL
October, 1977, Vol. 73, No. 10

Unemployed Epileptics Get Rehabilitation Services

West Virginia's Division of Vocational Rehabilitation is giving some special attention to the unemployed epileptic, Dr. Leslie F. McCoy, the agency's Assistant Director for Medical Services, has explained.

"The Division has site-visited special epileptic work programs in other states, hired part-time neurological and psychological consultants and set up a special program at its resident facility, the West Virginia Rehabilitation Center near Charleston, to attempt vocationally to salvage difficult cases," Doctor McCoy has noted. He added:

"The Division is accepting for services epileptics whom it would have passed over a few years ago as too severely handicapped to be rehabilitated.

"The younger (work-age) individual whose seizures have not been brought under control; whose emotional reaction to them has seriously dislocated his life adjustment, or whose over-protective family is blocking his self-sufficiency, are some of the types of cases in which the Division believes it can provide some vocational rehabilitation services through this more intensive effort.

"If you have a patient with seizures who faces significant risk of not getting into, or staying in, the ranks of the satisfactorily employed, the Division would like to have you refer that person to your local Division of Vocational Rehabilitation field office for inclusion in this project."

APPENDIX H

MEMORANDUM

TO:

FROM: David K. Steurer, CRC, Epilepsy Project Coordinator

SUBJECT: Referrals to Center Epilepsy Project

As you know, the Agency has recently initiated a new Innovation and Expansion Project at the West Virginia Rehabilitation Center for persons with poorly controlled epileptic seizures. The program is designed to provide services to persons that have been difficult to rehabilitate and referrals are being sought.

A recent survey of Agency rolls indicates that the following persons in your territory are coded as having epilepsy as a primary disability and may be possible candidates for the Project.

Name	SS	Age	Status
------	----	-----	--------

I would appreciate your reviewing the above named cases and consider their appropriateness for the Center Epilepsy Project.

Please feel free to contact me with any questions regarding the client's suitability for this program or other general concerns about the Epilepsy Project.

Your attention to this matter is greatly appreciated.

APPENDIX I

EPI-LAB DATA FORM

CARD 1

Biographical Data

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Data Collection Date

7 12

Name

13 ----- 32

SSN

33 ----- 41

Date of Birth

42 ----- 47

Sex

48

Marital Status

49

Living Arrangements

50

Number of Dependents

51 52

Number of People in Household

53 54

Relationship of Primary
Caretaker Day to Day

55 56

Educational Data

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Highest Grade Finished

7 8

Last Year in School

9 10

Elementary

11 12

Secondary

13 14

College

15 16

Vocational Technical

17 18

Education Certificates

19

Trade Certificates

20 21

Voc/Tech Major

22

EPI-LAB DATA FORM

CARD 3

CASEWORK DATA

Client Number	<u>1</u> <u>2</u>
Record Number	<u>3</u> <u>4</u>
Entry Number	<u>5</u> <u>6</u>
Territory	<u>7</u> <u>8</u> <u>9</u>
Primary Disability	<u>10</u> <u>11</u> <u>12</u>
Secondary Disability	<u>13</u> <u>14</u> <u>15</u>
Counselor Experience (yrs.)	<u>16</u> <u>17</u>
Rehabilitation Degree	<u>18</u>
Referral Source	<u>19</u> <u>20</u>
Currently Employed	<u>21</u>
Amount Per Month \$	<u>22</u> <u>23</u> <u>24</u>
SSI	<u>25</u>
SSI Amount Per Month \$	<u>26</u> <u>27</u> <u>28</u>
SSDI	<u>29</u>
SSDI Amount Per Month \$	<u>30</u> <u>31</u> <u>32</u>

CASEWORK DATA

Crippled Children Program

33

Clinic Service

34

Length of Service

35 36

Other Benefits

37

Other Benefits
Amount Per Month \$

38 40

Total Income

41 43

Maintenance

44

All Income Recorded

45

Previous VR Service

46 57

Previous WVRC Service

58 69

161

EMPLOYMENT HISTORY

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Most Recent Job Title

7 ----- 25

Most Recent Job DOT

26 ----- 28

Employer

29 ----- 48

Months of Continuous Employment

49 50

Job Starting Date

51 ----- 56

Job Ending Date

57 ----- 62

Special Training for Job

63 64

Type of Training

65

Length of Training

66 67

Training Source

68

Starting Salary in \$ Per Week

69 ----- 71

Highest Salary in \$ Per Week

72 ----- 74

Hours Worked Per Week, Excluding Overtime

75 76

EMPLOYMENT HISTORY CONT'D

Reason for Separation

77

Separation Due to Seizures

78

183

EMPLOYMENT HISTORY

Client Number

1 2

Record Number

3 4

Entry Number

5 6

2nd Most Recent Job Title

7 ----- 25

2nd Most Recent Job DOT

26 28

Employer

29 ----- 48

Months of Continuous Employment

49 50

Job Starting Date

51 ----- 56

Job Ending Date

57 ----- 62

Special Training for Job

63 64

Type of Training

65

Length of Training

66 67

Training Source

68

Starting Salary in \$ Per Week

69 ----- 71

Highest Salary in \$ Per Week

72 ----- 74

Hours Worked Per Week, Excluding Overtime

75 76

154

EMPLOYMENT HISTORY CONT'D

Reason for Separation

77

Separation Due to Seizures

78

155

EMPLOYMENT HISTORY

Client Number

1 2

Record Number

3 4

Entry Number

5 6

3rd Most Recent Job Title

7 ----- 25

3rd Most Recent Job DOT

26 ----- 28

Employer

29 ----- 48

Months of Continuous Employment

49 50

Job Starting Date

51 ----- 56

Job Ending Date

57 ----- 62

Special Training for Job

63 64

Type of Training

65

Length of Training

66 67

Training Source

68

Starting Salary in \$ Per Week

69 ----- 71

Highest Salary in \$ Per Week

72 ----- 74

Hours Worked Per Week, Excluding Overtime

75 76

156

EMPLOYMENT HISTORY CONT'D

Reason for Separation

77

Separation Due to Seizures

78

157

EMPLOYMENT HISTORY

Client Number

1 2

Record Number

3 4

Entry Number

5 6

4th Most Recent Job Title

7 ----- 25

4th Most Recent Job DOT

26 ----- 28

Employer

29 ----- 48

Months of Continuous Employment

49 50

Job Starting Date

51 ----- 56

Job Ending Date

57 ----- 62

Special Training for Job

63 64

Type of Training

65

Length of Training

66 67

Training Source

68

Starting Salary in \$ Per Week

69 ----- 71

Highest Salary in \$ Per Week

72 ----- 74

Hours Worked Per Week, Excluding Overtime

75 76

EMPLOYMENT HISTORY CONT'D

Reason for Separation

77

Separation Due to Seizures

78

189

EMPLOYMENT HISTORY

Client Number

1 2

Record Number

3 4

Entry Number

5 6

5th Most Recent Job Title

7 ----- 25

5th Most Recent Job DOT

26 ----- 28

Employer

29 ----- 48

Months of Continuous Employment

49 50

Job Starting Date

51 ----- 56

Job Ending Date

57 ----- 62

Special Training for Job

63 64

Type of Training

65

Length of Training

66 67

Training Source

68

Starting Salary in \$ Per Week

69 ----- 71

Highest Salary in \$ Per Week

72 ----- 74

Hours Worked Per Week, Excluding Overtime

75 76

170

EMPLOYMENT HISTORY CONT'D

Reason for Separation

77

Separation Due to Seizures

78

Best job to date

79

Best job (why)

80 81

Worst job to date

82

Worst job (why)

82 84

Months since last job

85 86

Job most affected by seizures

87

171

MEDICAL INFORMATION

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Date

7 — — — — 12

Current Diagnosis

13 — 15

Diagnosis Secondary

16 — 18

Diagnosis Tertiary

19 — 21

Type of Seizures

22 — 24

Date of Onset

25 — — — — 30

Age of Onset

31 32

Seizure Frequency

33 34

Etiology

35 36

Date of Last Seizure

SEIZURE BEHAVIOR37 — — — — 42

Loss of Consciousness

43

Falling

44

Sudden Jerking Movements

45

Aggressive or Rage Behavior

46

172

MEDICAL INFORMATION (CONT'D)

Tongue Biting	47
Incontinence	48
Purposeless but Inappropriate Acts	49
Momentary Staring	50
Cry or Shout	51
Injury to Self	52
Other	53
Other	54
Other	55
Run Away From Area and People	56
<u>SEIZURE CONSEQUENCY</u>	
Embarrassment	57
Headache	58
Unsteadiness of Gait	59
Nausea	60
Drowsiness	61
Confusion	62

173

EPI-LAB DATA FORM

CARD 9 (CONT'D)

MEDICAL INFORMATION (CONT'D)

Deep Sleep	63
Injury	64
<u>USUAL DISPOSITION</u>	
Emergency Room	65
Go to Bed	66
Requires Companion for 1 Hour or More	67
Other	68
<u>TIME OF DAY USUALLY OCCUR</u>	
Anytime	69
Evening	70
Forenoon	71
While Asleep	72
Afternoon	73
Night Only	74
Recovery Time (Minutes) to Normal Activity Level	75 76

174

EPI-LAB DATA FORM

CARD 10

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Date

7 12WAISVerbal IQ 13 15Performance IQ 16 18Full Scale IQ 19 21(Raw Scores)
Verbal

Inf

Comp

Arith

Simil

Dig Spa

Voc

22 2324 2526 2728 2930 3132 33

Performance

Dig Sym

Pic Com

Blk Des

Pic Arr

Obj Ass

34 3536 3738 3940 4142 43(Scale Scores)
Verbal

Inf

Comp

Arith

Simil

Dig Spa

Voc

44 4546 4748 4950 5152 5354 55

Performance

Dig Sym

Pic Com

Blk Des

Pic Arr

Obj Ass

56 5758 5960 6162 6364 65

175

EPI-LAB DATA FORM

CARD 11

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Test Date

7 12WRAT

Grade Level

Raw

Percentile

Reading

13 1516 1718 19

Spelling

20 2223 2425 26

Arithmetic

27 2930 3132 33

EPI-LAB DATA FORM

CARD 12

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Date

7 12Bell Adjustment Inventory

Home	Health	Social	Emotional	Occupational	Total
<u>13</u> <u>14</u>	<u>15</u> <u>16</u>	<u>17</u> <u>18</u>	<u>19</u> <u>20</u>	<u>21</u> <u>22</u>	<u>23</u> <u> </u> <u>25</u>

177

EPI-LAB DATA FORM

CARD 13

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Test Date

7 12Mooney Problem Checklist

H

ES

SI

P

HF

C

13 1415 1617 1819 2021 2223 24

S

R

O

Total

25 2627 2829 3031 33

178

EPI-LAB DATA FORM

CARD 14

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Date

7 12MMPI

(Raw Scores) L F K 1 2 3 4 5
 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28

 6 7 8 9 0
 29 30 31 32 33 34 35 36 37 38

(T Scores) L F K 1 2 3 4 5
 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54

 6 7 8 9 0
 55 56 57 58 59 60 61 62 63 64

179

EPI-LAB DATA FORM

CARD 15

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Test Date

7 — — — — 12CPI

Do

13 14

Cs

15 16

Sy

17 18

Sp

19 20

Sa

21 22

Wb

23 24

Re

25 26

So

27 28

Sc

29 30

To

31 32

Gi

33 34

Cm

35 36

180

EPI-LAB DATA FORM

CARD 15
(continued)

Ac

 $\overline{37}$ $\overline{38}$

Al

 $\overline{39}$ $\overline{40}$

Ie

 $\overline{41}$ $\overline{42}$

Py

 $\overline{43}$ $\overline{44}$

Fx

 $\overline{45}$ $\overline{46}$

Fe

 $\overline{47}$ $\overline{48}$

181

CLIENT: _ _ _ _ _

DATE: 1 _ _ _ _ 6

TENNESSEE SELF-CONCEPT:

Self Crit	T/F	Conflict		Positive Scores		Row 1	Row 2
		Net	Total	Total			
7 8	9	11	12 14	15 16	17 19	20 22	23 25

Row 3	Positive Scores						Total V.
	Col A	Col B	Col C	Col D	Col E		
26 28	29 30	31 32	33 34	35 36	37 38	39 41	

Variability		Distribution					
Col. Tot.	Row Tot.	D	5	4	3	2	1
42 43	44 45	46 48	49 50	51 52	53 54	55 56	57 58

Empirical Scales					
DP	GM	PSY	PD	N	PI
59 60	61 62 63	64 65	66 67	68 69	70 71

CLIENT NUMBER 74 _ 76

CARD NUMBER 77 _ _ 80

EPI-LAB FORM

CARD 17

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Date

7 — — — — 12I/E:13 14

183

EPI-LAB DATA FORM

CARD 18

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Test Date

7 — — — — 1216 PF

A B C D E F G H I

13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30

L M N O Q1 Q2 Q3 Q4

31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46

184

OUTCOME MEASURES

Client Number	<u>1</u> <u>2</u>
Record Number	<u>3</u> <u>4</u>
Entry Number	<u>5</u> <u>6</u>
Completed Epi-Lab	<u>7</u>
Number weeks in Epi-Lab	<u>8</u> <u>9</u>
Number cycles completed	<u>10</u>
Completed Vocational Evaluation	<u>11</u>
Entered vocational training	<u>12</u>
Completed vocational training	<u>13</u>
At end of grant period, in training, prognosis good for completion	<u>14</u>
At end of grant period, in training, prognosis poor for completion	<u>15</u>
Working	
competitive	<u>16</u>
sheltered	<u>17</u>
Withdrawal, program not completed	<u>18</u>

185

Withdrawal reasons

Medical	19
Psychiatric	20
Disciplinary (Behavioral problem)	21
(Violent behavior)	22
Poor motivation - uncooperative	23
Unable to adapt to WVRC environment	24
Extreme skill deficit	25
Learning problems	26
Improved in:	
medical aspects	27
independence aspects	28
behavioral aspects	29
dependability	30
motivation and attitude	31
Status at beginning of project	32 33
Status at end of project	34 35

EPI-LAB DATA FORM

CARD 20

MEDICATION

CLIENT NUMBER

1 2

RECORD NUMBER

3 4

ENTRY NUMBER

5 6

DATE

7 — — — — 12

MEDICATION NAME

DOSAGE

13 1425 — — 2815 1629 — — 3217 1833 — — 3619 2037 — — 4021 2241 — — 4423 2445 — — 48

197

placed on treatment unit
because of seizure-related
problem

29 30

other reason(not seizure related)

31 32

EPI-LAB DATA FORM

Clinic Visits

Client Number

1 2

Record Number

3 4

Entry Number

5 6

Period of Data

7 — — 10

Number of clinic visits during period

11 12

Number of M.D. contacts during period

13 14

Reasons for visits

seizure episode - no injury

15 16seizure episode - treated for
injury or other medical
intervention required17 18treatment of illness or injury
(not seizure related)19 20complaint - no treatment
provided21 22scheduled appointment (other
than neurological)23 24

neurological clinic

routine exam or follow-up

25 26problem of increased seizures,
medication side-effects, etc.27 28

APPENDIX J
CASE REVIEW FORM

PROSPECTIVE CLIENT: _____

CASE RECEIVED: _____

CASE REVIEWED BY COORDINATOR: _____
(date)

RECOMMENDATIONS: _____ ACCEPT _____ REJECT _____ HOLD

WHY?:

CASE REVIEWED BY PSYCHOLOGICAL CONSULTANT _____
(date)

RECOMMENDATIONS: _____ ACCEPT _____ REJECT _____ HOLD

WHY?:

CASE REVIEWED BY PSYCHIATRIC CONSULTANT _____
(date)

RECOMMENDATIONS: _____ ACCEPT _____ REJECT _____ HOLD

WHY?:

APPENDIX K

MEMORANDUM

April 6, 1977

TO: ALL CENTER STAFF

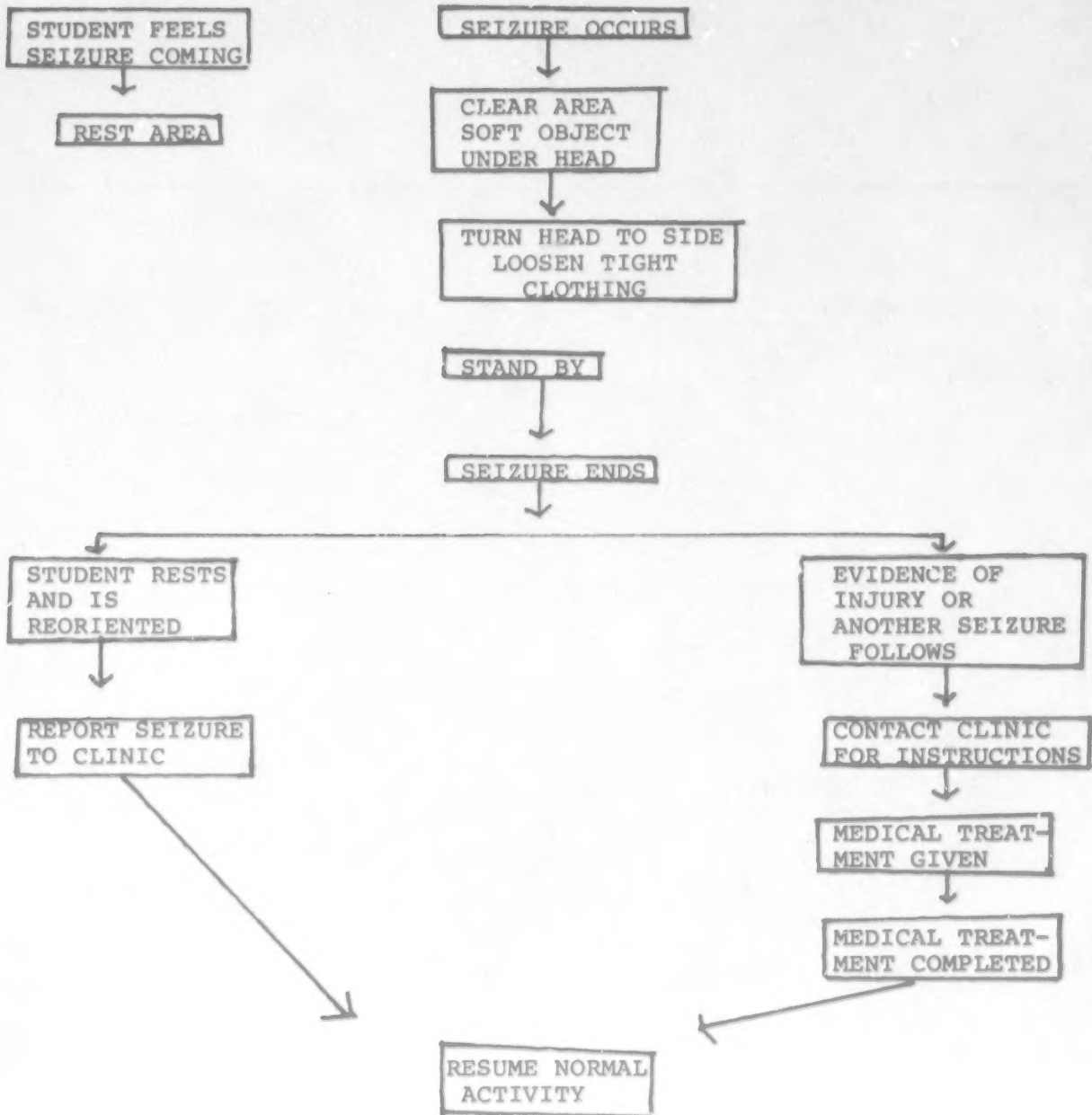
FROM: Thomas J. Janicki, M. D., Center Medical Director
George Gay, Administrator, WVRC

SUBJECT: WVRC Policy Regarding First Aid for Epileptic Seizures

In the event of an epileptic seizure, Center staff should take the following steps to insure that the proper attention is given:

1. KEEP CALM. The person is usually not suffering or in danger. You cannot stop a seizure once it has started so do not attempt to restrain or hold him.
2. CLEAR THE AREA of hard, sharp or hot objects which could injure him. Place a pillow or rolled up coat under his head.
3. DO NOT PUT ANYTHING BETWEEN HIS TEETH.
4. TURN THE PERSON'S HEAD TO THE SIDE. Loosen necktie and tight clothing.
5. DO NOT BE CONCERNED if he seems to stop breathing. DO BE CONCERNED if he passes from one seizure into another without gaining consciousness. This is a rare occurrence but requires a doctor's help.
6. STAND BY until the person has fully recovered consciousness and from the confusion which sometimes follows a seizure. Attempt to reduce the embarrassment and reorient him to his surroundings.
7. LET HIM REST if he feels tired, then encourage him to go about his regular activities.
8. CAREFULLY OBSERVE the person's actions during the seizure. This may be useful to medical or Rehabilitation personnel.
9. REPORT your observations to the Clinic. If there is personal injury, seek advice from the Clinic.

The attached flow diagram should serve as a guide for proper handling of seizure episodes throughout the Center.



APPENDIX L

INDIVIDUAL EPI-LAB PLAN

NAME:

STAFFING DATE:

UNDERSTANDINGS

This is your individual Epi-Lab plan or program. It contains understandings and a plan of action discussed with and agreed upon by you. It is understood that this plan is subject to change on the basis of changing circumstances. It is to be reviewed at least once each 12 week phase. These understandings and plan of action will serve as a readily visible means of direction and monitoring of our steps toward your overall adjustment and/or vocational attainment. In the course of the review you will be given an opportunity to review the plan and participate in its revisions. Of course, you may discuss a problem or grievance with your counselor at any time upon scheduling an appointment.

PLAN

Long-Term Epi-Lab Goals (meaning the ultimate end toward which all phases of work at Epi-Lab are directed; i.e., successful employment, independence, familial adjustment, etc.):

Phase # Objectives (means those targeted problems you will work on this phase as a step toward the ultimate goals stated above; example these objectives might be less dependence or improved reading skills):

Plan to Achieve Objectives (describe how each objective listed above will be achieved. For example, improved reading skills may be achieved by remedial education classes):

Evaluation Procedure (state how progress toward goals and objectives will be determined and a schedule for doing so. Example, work area progress will be determined by ratings done weekly):

Accomplishments:

Signature of student: _____
Date: _____

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APPENDIX M

EPI-LAB PERFORMANCE SUMMARY

I. PURPOSE:

One of the foremost aims of the Epilepsy Project was to observe, record, and later analyze clients' behavior as they individually and as a group participated in Project programming. While periodic psychometric assessment provided some measurement of client characteristics and change, there remained a significant gap which could only be filled by an assessment instrument specifically designed to tap the areas that the Epi-Lab program was intended to impact upon. The most significant gap was in the area of work or performance related behaviors.

Thus, the Epi-Lab Performance Rating was developed in order to:

1. provide an objective, quantifiable method of observing and recording assessment of client change in behavior and performance related assets and liabilities,
2. provide clients with feedback in regard to the estimation of their strong and weak areas, as well as their progress during the program,
3. quantify observational data to facilitate assessment, show client change and assist in client goal definition, and
4. establish criteria of performance for predicting client potential for various outcomes.

II. DEVELOPMENT OF RATING SCALE:

The Epi-Lab Performance Rating (See page M-21) resulted from the extensive review of existing instruments (Walls et.al., 1976), experimentation with different formats and items, and staff experience in working with this population. The original intent was to utilize an existing instrument but none was found which was appropriate for the population and program areas for which the program was designed. Many instruments that were examined were designed primarily for mentally retarded populations and contained items such as feeding and self-care behaviors and skills which were too elementary for the target population of the Project which was of average intelligence. Other rating scales were geared to educational skills such as reading and spelling and were thus not appropriate for program goals. The most comprehensive and most appropriate scales which were examined were the Adaptive Functioning Index (Marlett, 1971) and the Behavioral Characteristics

Progression (1973) but neither of these were broad enough in scope to fit the needs of the Project.

Thus, the Epi-Lab staff, after examining rating scales that were available, decided to develop the scale by utilizing ideas from other instruments and applying them to the philosophy and program content of the Epilepsy Project. The finalized format (See page M-21) is the result of 3 revisions and proved to be a valuable tool for the purposes for which it was intended.

It is significant to note that the instrument is not a standardized scale and predictive value is limited. Its primary value was in its capability to focus staff program planning to reveal clients areas of strength and weakness and to provide feedback to clients on performance in various areas. In the latter area, considerable variability in value was experienced due to client individual differences in ability to internalize and act on low ratings in deficit areas.

It is also significant that the instrument was intended for operational, not research, purposes. Its use with regard to identity of raters and time frequency of ratings was inconsistent and did not adhere to a definite design pattern, except that each client was rated during the first month of his program.

III. RATING SCALE FORMAT:

The Epi-Lab Performance Scale was intended to target five major areas of program content. All were defined by items listed under each category. Blanks were left in each category to provide for additional behaviors that were characteristic of specific clients. The target behavior space preceding each item was intended for staff use to check items of behavior that the client should concentrate upon during the upcoming period.

The five areas were:

1. Dependability: Primarily a work-related category of behaviors considered to be critical to potential for job success.
2. Independence: Also primarily a work-behavior category in which the behavior was observed primarily in the Epi-Lab Work Area.
3. Acceptance Skills: This category contains a list of behaviors that were found to be critical for this population. Often pronounced deficits in this area or on one item in some cases led to program failure. Behaviors were emitted in the Work Area, Groups, Recreation and all other program areas.
4. Motivation and Attitude: Behaviors in this area were manifested in all areas of program and were considered to be critical to client's ability to benefit from program intervention.

5. Medical Management: Items in this area were often difficult to measure and overlapped with other categories. However, the separate category was maintained because some clients had severe deficits in some of these items, particularly medication compliance, and feedback via the rating scale was important and necessary.

In order to provide clients with feedback from more than one staff member, and as a check on reliability of different staff, ratings were completed by the Work Area Supervisor, the Case-Aide, the Counselor, Recreation staff, and Interns. Clients also rated themselves so a comparison was possible between client and staff perception of performance in each behavioral area. All ratings were done independently by individual persons and transferred to the rating sheet only after each person had completed his rating separately.

The criteria for making an objective rating were difficult to establish. However, the critical areas of future overall (personal, marital, social and vocational) adjustment, and vocational success were kept in mind when ratings were performed. Thus, all behavior was judged in relation to its being an asset or a liability to future adjustment or vocational success.

Many items on the Rating Scale will be recognized as having much in common as those used on most behavior checklists or rating scales in a Rehabilitation setting. However, most items were the result of the experience of working with this population and observing their problems as manifested in all Epi-Lab program areas.

IV. OPERATIONAL USE OF FORM:

Prior to utilizing the rating scale, all raters were made aware of the importance of being objective, applying the definition of the criteria as stated, and rating independently without consulting others. Clients, as well as staff, were given the instructions and were provided further explanation in relation to the meaning of individual items and wording which may not have been completely understandable.

V. EVOLUTION AND CHANGE:

The Epi-Lab Performance Scale evolved through three forms before being finalized. Some items in the first version of the form which were borrowed from other forms did not apply as new clients entered the program. By the same token, some items used in the first version which were problems for the first or other classes did not have application to later groups. The final form of the Epi-Lab Performance Scale was an attempt to list and categorize only those items which were most common problems to most clients and those that would seem to be the most critical to eventual overall adjustment and vocational success.

TABLE 41
FIRST EPI-LAB PERFORMANCE RATINGS OF CLIENTS

RATED BEHAVIORS BY CATEGORY	CLIENT SELF RATINGS OF: (N=17)						STAFF RATINGS OF:			
	a		b		c		d		e	
	5		4 and below		3 and below		3.5 and below (N=17)		3.5 and below (N=27)	
	No.	%	No.	%	No.	%	No.	%	No.	%
DEPENDABILITY										
Meets production standard regularly	4	24	7	41	1	5	9	53	11	41
Arrives on time	10	59	8	47	3	18	12	71	16	59
Leaves on times	10	59	9	43	2	12	12	71	15	56
Is consistently present and participating (does not find excuses to be absent from assigned tasks)	12	71	7	41	1	5	10	59	12	44
Lets supervisor know about appointments	10	59	8	47	—	—	4	24	6	22
Keeps scheduled appointments	9	53	—	—	—	—	—	—	—	—
INDEPENDENCE										
Works on his own for more than 15 minutes once familiar with activity	13	76	6	35	1	5	8	47	9	33
Works through small disruptions	7	41	11	65	2	12	12	71	19	70
Avoids disruptive actions	7	41	10	59	2	12	14	82	16	59
Cooperates with the group to get the job done	9	53	10	59	—	—	12	71	19	70
Settles quickly into new situations	8	47	11	65	5	29	16	94	22	81
Tries to solve activity-related problems for himself before asking for help	8	47	11	65	2	12	15	88	18	67
Capable of working unsupervised	7	41	11	65	5	29	16	94	19	70
Schedules task to fit within time one has to do the job	8	47	11	65	3	18	14	82	15	56
Shows initiative (looks for things to do)	10	59	10	59	3	18	12	71	15	56
Can plan, start, and finish work on his own	6	35	13	76	4	24	13	76	22	81

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TABLE 41 (cont.)
FIRST EPI-LAB PERFORMANCE RATINGS OF CLIENTS (Cont'd)

RATED BEHAVIORS BY CATEGORY		CLIENT SELF RATINGS OF: (N=17)						STAFF RATINGS OF:			
		a		b		c		d		e	
		5		4 and below		3 and below		3.5 and below (N=17)		3.5 and below (N=27)	
		No.	%	No.	%	No.	%	No.	%	No.	%
INDEPENDENCE (cont'd)											
Looks after own supplies		10	59	8	47	2	12	16	94	10	37
Can make a decision requiring judgment		6	35	13	76	4	24	16	94	10	37
Knows quality of own work		6	35	12	71	4	24	13	76	19	70
ACCEPTANCE SKILLS											
Focus upon seizures (or other negative experiences) as reason for failure		2	12	2	12	1	5	7	41	—	—
Behaves appropriately for the situation		3	18	15	88	2	12	16	94	23	85
Appearance, presentation of self is favorable (posture, facial expression, behavior, other)		7	41	10	59	2	12	16	94	19	70
Keeps himself and clothing neat and clean		14	82	6	35	—	—	6	35	11	41
Can hold appropriate basic social conversation		5	29	14	82	6	35	11	65	15	56
Peer Relationships		6	35	12	71	4	24	15	88	19	70
Staff Relationships		9	53	10	59	4	24	16	94	22	81
Can give feedback appropriately		4	24	6	35	1	5	8	47	11	41
Disability does not interfere with interpersonal relationships		6	35	4	24	1	5	8	47	8	30
Maintains an even disposition		4	24	7	41	2	12	6	35	6	22
Maintains self-control (avoids hostile or explosive behaviors)		5	29	15	88	7	41	10	59	13	48
Can comfortably and appropriately discuss self and seizures in a facilitative way		5	29	5	29	3	18	8	47	8	30

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TABLE 41 (cont.)
FIRST EPI-LAB PERFORMANCE RATINGS OF CLIENTS (Cont'd)

RATED BEHAVIORS BY CATEGORY	CLIENT SELF RATINGS OF: (N=17)						STAFF RATINGS OF:			
	a		b		c		d		e	
	5		4 and below		3 and below		3.5 and below (N=17)		3.5 and below (N=27)	
	No.	%	No.	%	No.	%	No.	%	No.	%
MOTIVATION AND ATTITUDE										
Willing to try all tasks	15	88	4	24	1	5	5	29	8	30
Appears to be motivated by his task	7	41	11	65	3	18	12	71	15	56
Takes directions - demonstrates improvement	11	65	9	53	—	—	14	82	17	63
Demonstrates level of confidence equal to abilities	5	29	13	76	7	41	16	94	19	70
Willing to work on weak areas	7	41	3	18	2	12	4	24	4	15
Knows when he has a problem	10	59	9	53	2	12	15	88	23	85
Seeks advice for problems from appropriate source	4	24	5	29	2	12	8	47	12	44
Despite seizure related problems (i.e., medication, seizures, etc.) tries to meet expectations	12	71	7	41	2	12	12	71	14	52
Can accept feedback appropriately	5	29	13	76	4	24	12	71	16	59
Can benefit from constructive criticism	9	53	10	59	4	24	12	71	14	52
Sets realistic goals	3	18	6	35	5	29	4	24	7	26
Displays positive attitude	4	24	6	35	2	12	7	41	7	26
MEDICAL MANAGEMENT										
Complies with medication	8	47	2	12	—	—	1	5	3	11
Maintains proper diet	5	29	5	29	2	12	3	18	3	11
Participates in activities which promote physical fitness	6	35	4	24	1	5	4	24	3	11
Maintains good dental hygiene	3	18	7	41	2	12	3	18	3	11

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VI. ANALYSIS AND INTERPRETATION:

Of course, any analysis or interpretation of data taken from the Epi-Lab Performance Scale must be made with full awareness of the original intent of the Rating Scale, its operational utilization, and its evolution through three versions. It is not a standardized research instrument and, thus, should not be used as an indication of individual client change. However, it does have value in providing information descriptive of the group of 28 clients served in Epi-Lab. With this in mind, some analysis of the Rating Scale can be made.

For the purpose of analysis, only the ratings of the full-time staff were utilized because other staff ratings were not consistently applied and thus skewed the results.

Client self ratings were available only on 17 clients.

Staff ratings are available on 27 of the 28 clients served in Epi-Lab.

Several questions which can be answered by analysis of the Epi-Lab Performance Scale are as follows:

- (1) What problems were experienced most frequently by all clients at entry into Epi-Lab based upon the ratings of full-time staff?

Source: Average of staff ratings on first rating accomplished on all 27 clients.

"Problem" defined as an average rating of 3.5 or below.

Interpretation: See Table 41, column e.

Behaviors that had an average staff rating of 3.5 or below for 50% or more of all 27 clients are ranked by percentage below:

DEPENDABILITY

Arrives on time	59%
Leaves on time	56%

INDEPENDENCE

Settles quickly into new situations	81%
Can plan, start, and finish work on his own	81%
Works through small disruptions	70%
Cooperates with the group to get the job done	70%
Capable of working unsupervised	70%
Knows quality of own work	70%
Tries to solve activity-related problems for himself before asking for help	67%

INDEPENDENCE (Cont'd)

Avoids disruptive actions	59%
Schedules task to fit within time one has to do the job	56%
Shows initiative (looks for things to do)	56%

ACCEPTANCE SKILLS:

Behaves appropriately for the situation	85%
Staff relationships	81%
Appearance, presentation of self is favorable (posture, facial expression, behavior, other)	70%
Peer relationships	70%
Can hold appropriate basic social conversation	56%
Maintains self-control (avoids hostile or explosive behaviors)	48%

MOTIVATION AND ATTITUDE:

Knows when he has a problem	85%
Demonstrates level of confidence equal to abilities	70%
Takes direction - demonstrates improvement	63%
Can accept feedback appropriately	59%
Appears to be motivated by his task	56%
Despite seizure related problems (i.e. medication, seizures, etc.) tries to meet expectations	52%
Can benefit from constructive criticism	52%

MEDICAL MANAGEMENT:

None

- (2) What problems were experienced most frequently by the 17 clients who rated themselves based upon the ratings of full-time Epi-Lab staff?

Source: Average of staff ratings on first rating accomplished on 17 clients. Problem defined as average rating of 3.5 or below.

Interpretation:

See Table 41, column d.

Behaviors that had an average staff rating of 3.5 or below for 50% or more of all 17 clients are ranked by percentage below:

DEPENDABILITY:

Arrives on time	71%
Leaves on time	71%
Is consistently present and participating	59%
Meets production standards regularly	53%

INDEPENDENCE

Settles quickly into new situations	94%
Capable of working unsupervised	94%
Can make a decision requiring judgement	94%
Tries to solve activity-related problems for himself before asking for help	88%
Avoids disruptive actions	82%
Schedules task to fit within time one has to do the job	82%
Can plan, start, and finish work on his own	76%
Knows quality of own work	76%
Works through small disruptions	71%
Cooperates with the group to get the job done	71%
Shows initiative (looks for things to do)	71%

ACCEPTANCE SKILLS:

Behaves appropriately for the situation	94%
Appearance, presentation of self is favorable (posture, facial expression, behavior, other)	94%
Staff relationships	94%
Peer relationships	88%
Can hold appropriate basic social conversation	65%
Maintains self-control (avoids hostile or explosive behaviors)	59%

MOTIVATION AND ATTITUDE:

Demonstrates level of confidence equal to abilities	94%
Knows when he has a problem	88%
Takes direction - demonstrates improvement	82%
Appears to be motivated by his task	71%
Despite seizure related problems (i.e. medication, seizures, etc.) tries to meet expectations	71%
Can accept feedback appropriately	71%
Can benefit from constructive criticism	71%

MEDICAL MANAGEMENT:

None

- (3) What problems were experienced most frequently by the 17 clients who rated themselves based upon their own ratings?

Source: Client self ratings of 4.0 and below by those 17 clients who rated themselves upon entry into Epi-Lab. (Note: 4.0 was used as cut off due to halo effect noted in client ratings (see Table 00). Clients did not rate themselves 3 or below with enough frequency to enable discrimination of areas that they judged as problems).

Interpretation:

See Table 41, column b.

Behaviors that had an average client rating of 4.0 or below for 50% or more of the 17 clients are ranked by percentage below:

DEPENDABILITY:

None

INDEPENDENCE:

Can plan, start, and finish work on his own	76%
Can make a decision requiring judgement	76%
Knows quality of own work	71%
Works through small disruptions	65%
Settles quickly into new situations	65%
Tries to solve activity-related problems for himself before asking for help	65%
Capable of working unsupervised	65%
Schedules task to fit within time one has to do the job	65%
Avoids disruptive actions	59%
Cooperates with the group to get the job done	59%
Shows initiative	59%

ACCEPTANCE SKILLS:

Behaves appropriately for the situation	88%
Maintains self-control (avoids hostile or explosive behaviors)	88%
Can hold appropriate basic social conversation	82%
Peer relationships	71%
Appearance, presentation of self is favorable (posture, facial expression, behavior, other)	59%
Staff relationships	59%

MOTIVATION AND ATTITUDE:

Demonstrates level of confidence equal to abilities	76%
Can accept feedback appropriately	76%
Appears to be motivated by his task	65%

Can benefit from constructive criticism	59%
Takes direction - demonstrates improvement	53%
Knows when he has a problem	53%

MEDICAL MANAGEMENT:

None

- (4) Which of the five categories of behaviors were perceived by staff as being problems for most clients?

Source: Average of number of all 27 clients experiencing all problems within each category.

Interpretation:

See Table 41, column e.

Rank by average number:

INDEPENDENCE	16.38
ACCEPTANCE SKILLS	14.09
MOTIVATION AND ATTITUDE	13.23
DEPENDABILITY	12.00
MEDICAL MANAGEMENT	3.00

- (5) Do clients and staff perceive common problems?

Source: Compare clients' ratings (Table 41b) with staff ratings (Table 41d) and identify those behaviors defined as problems 50% or more of the time by each. Also, list those identified by staff and not clients, clients and not staff.

Note: Because of halo effect or clients' reluctance to rate themselves 3 or below, it is not possible to use a client rating of 3.5 or below to define their perceived problem areas. Thus, the only comparison which is possible is to select those items rated 4 or below and assume that a client rating of 4 is an acknowledgement of some deficit, even though the definitions of the rating criteria define 4 as "adequate."

Interpretation:

Behaviors seen as problems by staff and clients:

DEPENDABILITY

<u>STAFF</u>	<u>CLIENT</u>
--------------	---------------

None

INDEPENDENCE

Settles quickly into new situations	94%	65%
Capable of working unsupervised	94%	65%
Can make a decision requiring judgement	94%	76%
Tries to solve activity-related problems for himself before asking for help	88%	65%
Avoids disruptive actions	82%	59%
Schedules task to fit within time one has to do the job	82%	65%
Can plan, start, and finish work on his own	76%	76%
Knows quality of own work	76%	71%
Works through small disruptions	71%	65%
Cooperates with the group to get the job done	71%	59%
Shows initiative (looks for things to do)	71%	59%

ACCEPTANCE SKILLS:

Behaves appropriately for the situation	94%	88%
Appearance, presentation of self is favorable (posture, facial expression, behavior, other)	94%	59%
Staff relationships	94%	59%
Peer relationships	88%	71%
Can hold appropriate basic social conversation	65%	82%
Maintains self-control (avoids hostile or explosive behavior)	59%	88%

MOTIVATION AND ATTITUDE:

Demonstrates level of confidence equal to abilities	94%	76%
Knows when he has a problem	88%	53%
Takes direction - demonstrates improvement	82%	53%
Appears to be motivated by his task	71%	65%
Can accept feedback appropriately	71%	76%
Can benefit from constructive criticism	71%	59%

Behaviors seen as problems by staff only:

DEPENDABILITY

Arrives on time	71%
Leaves on time	71%
Is consistently present and participating	59%
Meets production standards regularly	53%

INDEPENDENCE:

None

ACCEPTANCE SKILLS:

None

MOTIVATION AND ATTITUDE:

Despite seizure related problems (i.e. medication, seizures, etc.) tries to meet expectations

71%

Behaviors seen as problems by clients only:

DEPENDABILITY:

None

INDEPENDENCE:

None

ACCEPTANCE SKILLS:

None

MOTIVATION AND ATTITUDE:

None

MEDICAL MANAGEMENT:

Maintains good dental hygiene

41%

DISCUSSION:

A review of this comparison might suggest that the clients did not view themselves as having any problems with 'Dependability' behaviors, while staff did see four problems existing in more than half of the seventeen clients. 'Independence' behaviors were acknowledged by both, but ranked in different order of frequency. 'Acceptance Skills' behaviors were seen as problems by both, but clients viewed themselves as having more problems with 'maintaining self control' (88%) and, 'holding appropriate basic social conversation' (82%), while staff thought that 'appropriate behavior' (94%), 'appearance', 'presentation of self' (94%) and, 'staff relationships' (94%) were the most frequent problem behaviors. 'Motivation and Attitude' were problems acknowledged by staff and clients alike, though there is a difference in ranking. The staff identified that 71% of the seventeen clients had problems with 'meeting expectations despite seizure related problems'

- (6) Did staff ratings, by five categories, of entering clients relate to positive or negative outcomes?

Definitions: Positive outcomes: clients who completed training or are in training with good prognosis, or are working.

Negative outcomes: clients who are in training with poor prognosis or withdrew from program - incomplete.

Source: Compare average category ratings in Table 42 and 43 of 19 clients who had definite outcomes at end of Project.

Interpretation:

	<u>(+)Outcome</u>	<u>(-)Outcome</u>	<u>Difference</u>
DEPENDABILITY	3.65	3.26	+.39
INDEPENDENCE	3.13	2.84	+.29
ACCEPTANCE SKILLS	3.15	2.75	+.40
MOTIVATION AND ATTITUDE	3.08	2.80	+.28

In all four categories, staff ratings were high for clients with positive outcomes.

- (7) Were staff ratings for clients with positive outcomes higher than for those who involuntarily withdrew because of behavior problems?

Source: Compare average category ratings in Table 42 with those in Table 44 of 19 clients who had definite outcomes at end of Project.

Interpretation:

	<u>(+)Outcome</u>	<u>Withdrew Behavior Problem</u>	<u>Difference</u>
DEPENDABILITY	3.65	3.42	+.23
INDEPENDENCE	3.13	2.75	+.38
ACCEPTANCE SKILLS	3.15	2.48	+.67
MOTIVATION AND ATTITUDE	3.08	2.43	+.65

In all four areas, staff ratings were higher, especially in Acceptance Skills and Motivation and Attitude.

- (8) Were client ratings of themselves higher than staff ratings?

Source: Compare overall average client ratings with all average staff ratings for 26 clients who rated themselves.

See Table 45.

TABLE 42
FIRST STAFF RATINGS
OF CLIENTS WITH POSITIVE OUTCOMES*
(N=19)

DEPENDABILITY

Client No.	Rating
2	3.66
3	2.83
4	4.37
8	3.98
24	3.41

Average Rating: 3.65

ACCEPTANCE SKILLS

Client No.	Rating
2	2.23
3	2.06
4	3.58
8	4.23
24	3.63

Average Rating: 3.15

INDEPENDENCE

Client No.	Rating
2	2.23
3	3.17
4	3.71
8	3.98
24	2.56

Average Rating: 3.13

MOTIVATION AND ATTITUDE

Client No.	Rating
2	2.81
3	2.36
4	3.55
8	3.56
24	3.10

Average Rating: 3.08

*Clients who completed training; in training/prognosis good; working.

TABLE 43

**FIRST STAFF RATINGS
OF CLIENTS WITH NEGATIVE OUTCOMES*
(N=19)**

DEPENDABILITY

Client No.	Rating
6	3.00
7	3.50
9	3.75
10	3.16
11	2.50
12	2.37
13	2.44
14	3.37
15	3.25
16	4.16
17	3.62
19	3.00
21	3.33
22	3.86
23	3.66

Average Rating: 3.26

ACCEPTANCE SKILLS

Client No.	Rating
6	2.64
7	1.61
9	3.58
10	2.45
11	3.66
12	2.83
13	2.47
14	3.04
15	2.89
16	2.80
17	2.23
19	2.88
21	2.92
22	3.56
23	1.69

Average Rating: 2.75

INDEPENDENCE

Client No.	Rating
6	2.38
7	2.11
9	4.00
10	2.59
11	3.33
12	3.22
13	2.36
14	3.04
15	2.95
16	3.11
17	2.72
19	2.50
21	2.34
22	3.66
23	2.39

Average Rating: 2.84

MOTIVATION AND ATTITUDE

Client No.	Rating
6	2.42
7	1.66
9	3.00
10	1.80
11	3.35
12	3.11
13	2.40
14	2.85
15	2.98
16	3.10
17	2.60
19	3.23
21	3.76
22	4.05
23	1.74

Average Rating: 2.80

*Clients in training/prognosis poor; withdrawal/
program not completed.

TABLE 44
FIRST STAFF RATINGS
OF CLIENTS WITH BEHAVIORAL PROBLEMS
AS REASON FOR WITHDRAWAL
(N=19)

DEPENDABILITY

Client No.	Rating
7	3.50
9	3.75
10	3.16
15	3.25
17	3.62
19	3.00
23	3.66

Average Rating: 3.42

ACCEPTANCE SKILLS

Client No.	Rating
7	1.61
9	3.58
10	2.45
15	2.89
17	2.23
19	2.88
23	1.69

Average Rating: 2.48

INDEPENDENCE

Client No.	Rating
7	2.11
9	4.00
10	2.59
15	2.95
17	2.72
19	2.50
23	2.39

Average Rating: 2.75

MOTIVATION AND ATTITUDE

Client No.	Rating
7	1.66
9	3.00
10	1.80
15	2.98
17	2.60
19	3.23
23	1.74

Average Rating: 2.43

TABLE 45
COMPARISON OF ALL AVERAGE RATINGS
CLIENT AND STAFF
(N=26)

Client No.	Date	Client	Staff	Difference*
2	9/30/77	4.21	2.39	+1.82
	3/17/78	4.56	3.56	+1.00
3	9/30/77	3.85	2.61	+1.24
	12/2/77	4.43	3.69	+ .74
4	9/30/77	3.89	3.80	+ .09
	12/2/77	3.85	3.80	+ .05
6	10/14/77	3.69	2.61	+1.08
7	10/14/77	4.23	2.22	+2.01
	3/17/78	4.02	3.21	+ .81
8	10/14/77	3.75	3.98	- .23
9	10/14/77	4.21	3.58	+ .63
	10/21/77	4.39	2.35	+2.04
	9/29/78	3.75	2.92	+ .83

TABLE 45 (cont.)

10	2/17/78	4.19	2.50	+1.69
	9/23/78	4.65	2.65	+2.00
	10/20/78	4.59	2.90	+1.69
11	2/17/78	4.40	3.21	+1.19
12	2/17/78	4.81	2.88	+1.93
	3/17/78	4.87	3.22	+1.65
13	2/17/78	3.91	2.41	+1.30
14	2/17/78	3.95	3.07	+ .88
	9/29/78	4.52	3.39	+1.13
15	9/23/78	4.02	3.70	+ .32
	10/20/78	3.17	4.00	- .83
16	9/23/78	3.21	3.26	- .05
	10/20/78	4.26	3.79	+ .47
17	-	-	-	No client ratings
18	-	-	-	No ratings at all
19	9/29/78	4.57	3.29	+1.28
	10/20/78	4.54	3.74	+ .80
20	9/29/78	4.08	2.51	+1.57
	10/20/78	4.25	3.39	+ .86
	2/2/79	4.24	3.58	+ .66
21	2/2/79	3.78	3.00	+ .78
22	2/2/79	4.06	3.85	+ .21
23	2/2/79	4.84	2.37	+2.47
24	2/2/79	4.10	3.19	+ .91
25	3/30/79	4.15	3.34	+ .81
26	3/30/79	4.23	3.61	+ .62
27	3/30/79	4.90	2.85	+2.05
28	3/30/79	4.97	2.29	+2.68

*+Client Rating Higher; -Client Rating Lower

TABLE 46

FIRST AND LAST AVERAGE RATINGS
OF CLIENTS BY STAFF
(N=17)

Client No.	Pre Date	Rating	Post Date	Rating	Direction of Change
2	9/30/77	2.39	4/28/78	3.00	+
3	9/30/77	2.61	12/2/77	3.69	+
4	9/30/77	3.80	12/2/77	3.80	
6	10/14/77	2.61	12/9/77	2.77	+
7	10/14/77	2.22	4/28/78	3.84	+
8	10/14/77	3.98	12/2/77	4.12	+
9	10/14/77	3.58	10/20/78	2.00	-
10	2/17/78	2.50	10/20/78	2.90	+
11	2/17/78	3.21	7/28/78	3.23	+
12	2/17/78	2.88	3/17/78	3.22	+
13	2/17/78	2.41	4/14/78	2.36	-
14	2/17/78	3.07	10/20/78	3.37	+
15	6/13/78	3.01	10/20/78	4.00	+
16	6/13/78	3.23	10/20/78	3.79	+
17	6/13/78	2.73	7/28/78	2.21	-
19	9/29/78	3.29	10/20/78	3.74	+
20	9/29/78	2.51	2/2/79	3.58	+

Interpretation: Of 39 total ratings, 6 client self ratings were 2 or more rating points higher than staff ratings, 13 were between 1 and 1.99 points higher, 12 were .50 to .99 points higher and 5 were .01 to .49 points higher. Only 3 of the 39 client self ratings were lower than the staff rating.

This result could be due to client halo effect, lack of insight, lack of skill and objectivity as a rater, over criticalness by the staff, or any number of reasons. However, subjective observation of client inability or unwillingness to address or acknowledge deficit areas would support this rating data.

- (9) Which clients showed positive change in staff pre-post ratings and was their outcome positive or negative?

Definition: Positive change: improvement in rating above 3.5.

Positive outcome: completed training; in training/prognosis good; working.

Negative outcome: in training/prognosis poor; withdrew-not completed.

Source:

Table 46

N=17 - 17 clients rated themselves more than once

Comparison is between first-last available rating.

<u>CLIENT #</u>	<u>POSITIVE CHANGE</u>	<u>FINAL RATING</u>	<u>OUTCOME</u>
2	No	3.00	+
3	Yes	3.69	+
4	Yes	3.80	+
6	No	2.77	-
7	Yes	3.84	-
8	Yes	4.12	+
9	No	2.00	-
10	No	2.90	-
11	No	3.23	-
12	No	3.22	-
13	No	2.36	-
14	No	3.37	-
15	Yes	4.00	-

<u>CLIENT #</u>	<u>POSITIVE CHANGE</u>	<u>FINAL RATING</u>	<u>OUTCOME</u>
16	Yes	3.79	-
17	No	2.21	-
19	Yes	3.74	-
20	Yes	3.58	-

As can be seen, even though staff ratings showed change, they did not predict client outcome as defined above.

VII. RECOMMENDATIONS FOR FUTURE USES:

The Epi-Lab Performance Scale may be of value to other personnel who are concerned with the behavior of epileptic clients similar to the population served in this study. A realistic assessment of its value would depend upon a more standardized approach to its utilization and evaluation of obtained results. Deficits in the interpretation of the use of this instrument in the Epi-Lab Project are due to inconsistent utilization of the form and lack of conformity to research design specifications in its utilization. If these factors were corrected, a more thorough analysis of its usefulness may be possible.

EPI-LAB PERFORMANCE SUMMARY

CLIENT: _____ DATE: _____

RATINGS BASED ON PERIOD OF OBSERVATION FROM _____ TO _____

Criteria to be used for rating:

- 5 - Major Asset - Behavior will make a significant contribution to overall adjustment and enhance vocational success.
- 4 - Adequate - Behavior will favorably influence overall adjustment and vocational success
- 3 - Functional - Not a major asset but could interfere with overall adjustment and vocational success.
- 2 - Inadequate - Behavior will limit overall adjustment or vocational success.
- 1 - Major liability - Behavior is a barrier to overall adjustment or vocational success.
- X - Not observed

Key: CL-Client
 WA-Work Area Supervisor
 CN-Counselor

CA-Case-Aide
 RC-Recreation

Targeted Behavior	DEPENDABILITY	CL	WA	CN	CA	RC
_____	Meets production standard regularly . . .					
_____	Arrives on time					
_____	Leaves on time					
_____	Is consistently present and participating (does not find excuses to be absent from assigned tasks).					
_____	Lets supervisor know about appointments .					
_____	Keeps scheduled appointments					

Targeted Behavior	INDEPENDENCE	CL	WA	CN	CA	RC
_____	Works on his own for more than 15 minutes once familiar with the activity					
_____	Works through small disruptions					
_____	Avoids disruptive actions					
_____	Cooperates with the group to get the job done					
_____	Settles quickly into new situations . .					
_____	Tries to solve activity-related problems for himself before asking for help . . .					

MOTIVATION AND ATTITUDE

M-23

APPENDIX N

MEMORANDUM

TO: EPI-LAB

FROM:

SUBJECT: Seizure Episode Report

INSTRUCTIONS:

Complete this form as soon as possible after seizure. Check only the things you observe or the things you remember. Don't be concerned if you do not observe everything. Mail form to Epi-Lab at your first opportunity.

CLIENT: _____ DATE: _____

OBSERVER: _____ PLACE: _____

TIME FACTORS:

Time of occurrence: _____

Time ended: _____

Recovery time: _____ (time it took client to get back to and function normally on activities interrupted by seizure.)

PRE-SEIZURE:

What was client doing or saying just before seizure occurred?

Did any of the following occur:

_____ loud noise _____ flickering light
 _____ outburst of anger _____ feelings of anxiety
 _____ warning of any kind (what?) _____

DESCRIPTION OF SEIZURE EPISODE:

_____ cry or shout	_____ momentary stare or pause
_____ fall or drop	_____ eyes blink
_____ movement _____ generalized	_____ head turning to _____ R
_____ _____ local	_____ _____ L
_____ rigidity	_____ stopped breathing
_____ tongue biting	_____ shaking movements
_____ unconsciousness	_____ incontinence
_____ fingering clothing	_____ purposeful but inappropriate behavior
_____ lip smacking	_____ behavioral or emotional
_____ sudden jerking of arm, head,	_____ outburst
_____ leg on one side _____ R	_____ other
_____ _____ L	
_____ Injury (type) _____	

AFTER SEIZURE:COMMENTS:

_____ confusion
 _____ unsteady on feet
 _____ embarrassment
 _____ drowsy
 _____ headache
 _____ sleep
 _____ nausea
 _____ other

APPENDIX O

EPILEPSY QUIZ

Directions: This is a true-false quiz. Circle the appropriate answer. If your answer is false, write the correct answer on the line provided.

- T F 1. Epilepsy is a relatively new disease which has been intriguing and mystifying mankind for the last 10 centuries.

- T F 2. Today it is estimated that approximately 1 million people in the U.S., or 2% of the population have epilepsy.

- T F 3. Epilepsy is a general condition that takes different forms and is associated with brain disorder.

- T F 4. Epilepsy is a separate disease rather than a symptom.

- T F 5. Epilepsy is characterized by the possibility of recurrent sudden attacks.

- T F 6. Most doctors agree that the basic cause of epilepsy is an injury, however slight, to some portion of the brain.

- T F 7. Early signs or symptoms of a seizure episode can include sudden loss of muscle tone or control, inappropriate behavior, short staring episodes, or daydreaming and sudden tenseness or involuntary jerking of a part of the body.

- T F 8. A seizure is a disturbance of the normal pattern of electrical activity in the brain.

- T F 9. There are three major categories or types of seizures.
-
- T F 10. The aura or warning is not a part of the seizure itself.
-
- T F 11. The most serious type of generalized seizure is known as grand mal.
-
- T F 12. Focal seizures are that type in which the abnormal electrical activity begins at one point in the brain and remains relatively localized.
-
- T F 13. The kind of seizure a person will have is different each time and, therefore, unpredictable.
-
- T F 14. Insults to the brain may cause seizures. Some common insults are physical trauma, infections, and toxins.
-
- T F 15. The cause of seizures is always known.
-
- T F 16. Everyone with epilepsy experiences convulsive movements, however slight, during seizure episodes.
-
- T F 17. During a typical absence seizure, the person stares and is out of contact with his surroundings.
-
- T F 18. Post-ictal, or after seizure symptoms, may include confusion, drowsiness, abnormal sleep, agitation, irritability, headache, and other.
-
- T F 19. Most epileptic persons take medication in order to achieve some measure of control over seizure attacks. These medications are called anti-convulsants.
-

- T F 20. Probably the major cause for treatment failure, meaning failure to achieve the best possible control for a given epileptic person, is poor compliance in taking medication.
-
- T F 21. When adjusting seizure medication, the doctor must consider not only seizure control, but also social functioning and mental alertness.
-
- T F 22. Common anti-convulsant drug side effects are drowsiness, unsteady gait (drunkenness), slurred speech.
-
- T F 23. Only one-fifth or 20% of persons with seizures can achieve full control of their seizures.
-
- T F 24. Medicines cure epilepsy?
-
- T F 25. Goals for anti-convulsant therapy involve stopping all seizures without regard to side effects.
-
- T F 26. Epilepsy can be diagnosed by an EEG (brain wave test) by itself.
-
- T F 27. Many people with epilepsy become emotionally dependent because of the way others over-protect them rather than the seizure disorder itself.
-
- T F 28. In some persons with epilepsy, problems of withdrawal or anti-social behavior are equal to seizure control problems.
-
- T F 29. Changing a person's behavior may change his seizures.
-
- T F 30. The epileptic seizure itself often involves biosystem responses that are alien, bizarre, and frightening to the uninitiated, thus accounting partially for societal fear of epilepsy.
-

- T F 31. The person with epilepsy has more difficulty developing a positive self-concept than other disabled persons because of the unpredictable, intercurrent visibility of his handicap.
-
- T F 32. Most children with epilepsy should not be exposed to the rigors of public schooling.
-
- T F 33. People with epilepsy are usually lower in intelligence than the general population.
-
- T F 34. If you have epilepsy you can get a driver's license.
-
- T F 35. If they take away your driver's license, you can never get it back if you have epilepsy.
-
- T F 36. Studies show the accident involvement rate of epileptic drivers is considerably higher than that of unimpaired drivers.
-
- T F 37. People with epilepsy cannot get married.
-
- T F 38. Epilepsy can be inherited directly from one's parents.
-
- T F 39. Jobs for persons with epilepsy should be available without any restrictions.
-
- T F 40. Employers hesitate to hire people with epilepsy because of the public image of the epileptic person, the concern that other employees will be hindered by their fears of the epileptic worker, and primarily the idea that people with epilepsy are accident prone and will cause Workmen's Compensation insurance premiums to increase.
-

- T F 41. Outside of seizure control, the most difficult problem with the jobseeker with epilepsy is lack of education and training.
-
- T F 42. Workmen's Compensation premiums are higher for organizations that employ persons with epilepsy.
-
- T F 43. Workers with convulsive disorders have a higher rate of absenteeism than other workers.
-
- T F 44. The purpose of the second or subsequent injury fund adopted by most states is to restrict the employer's liability to only the amount of the second injury.
-
- T F 45. Most insurance rates are higher for persons with epilepsy.
-
- T F 46. Epilepsy may be prevented by genetic counseling and evaluation for prospective parents, medical supervision during pregnancy, reduction of serious head injuries, and their causes, and eradication of severe infectious diseases.
-

Directions:

These are multiple choice questions. Circle the letter of the appropriate response.

1. In the event of an epileptic seizure, the observer should take the following action to help the seizing person:
 - a. Attempt to restrain or hold the person
 - b. Slap the person's face to restore consciousness
 - c. Clear the area of hard, sharp, or hot objects which could injure him.
 - d. Get medical help immediately.
2. During a seizure, place the following object in the person's mouth.
 - a. A wet washcloth or towel
 - b. A padded tongue blade
 - c. A clean finger

- d. Nothing
3. If a seizing person seems to stop breathing:
- a. Do not be concerned, breathing will resume spontaneously when the attack ceases
 - b. Death is eminent
 - c. Brain damage will occur
 - d. Give the person artificial resuscitation.
4. It is anatomically impossible for a person to swallow his tongue during a seizure, however, the tongue may become limp and slide backward obstructing the trachea following the attack. This can be alleviated by:
- a. Putting a tongue blade in the person's mouth
 - b. Turning the person's head to one side after the muscular contractions of the seizure are over
 - c. By sitting the person up
 - d. By holding the tip of the person's tongue during the post-ictal phase.
5. As the person regains consciousness, it is important to keep talking to him for purposes of:
- a. Reassuring and reorienting the person
 - b. Checking his recall
 - c. Gaining valuable information about thought patterns following seizure episodes
 - d. Stimulating waking centers of the brain.

CLIENT:
DATE:

ANTICONVULSANT DRUGS
SIDE EFFECTS

NAME OF ANTICONVULSANT DRUG	NAUSEA	RASH	ANOREXIA	ATAXIA	DROWSINESS	DIZZINESS	TREMOR	IRRITABILITY	HEADACHE	GINGIVAL HYPERPLASIA	HIRSUTISM	BLURRED VISION	AVERAGE DAILY DOSE	PRESENT DOSE
CLONOPIN			X	X	X		X				X		1.5-20mg	
DIAMOX			X		X								250-1000 mg	
DILANTIN	X	X		X						X	X		100-400 mg	
LIBRIUM	X	X		X	X								30-75 mg	
MEBARAL	X	X				X			X				400-600 mg	
MESANTOIN		X		X	X		X					X	0.2-0.6 gm	
MYSOLINE			X	X	X			X					250-1000 mg	
PARADIONE	X	X	X									X	600 mg-2.4 gm	
PHENOBARBITAL					X			X					100 mg	
PHENURONE			X		X								2-3 gm	
TEGRETOL	X	X	X		X	X						X	600-1200 mg	
VALIUM				X	X		X		X				4-40 mg	
ZARONTIN	X		X		X	X			X				500mg., 1.5 gm	
DEPAKENE	X				X								250-1250 mg	

X INDICATES POSSIBLE SIDE-EFFECTS

(X) INDICATES OBSERVED SIDE EFFECTS

APPENDIX Q

WORK ACTIVITIES

Work Area tasks were activities ranging from the simple, routine repetitive types to the highly complex. The tasks were selected because of their value as tools in the evaluation process and not because they represented any valuable learning experience in themselves. In the performance of each task certain specific work traits were to be observed.

A number of factors limited the types of activities selected for the Work Area. First, because this was an uncontrolled epileptic population, particular consideration had to be given to the safety of the task, for example, no dangerous equipment with moving parts could be used. Further, activities involving heat, sharp objects, and height had to be avoided. Second, in developing activities for any population, consideration had to be given to individual differences in intelligence, performance skills, secondary disabilities, backgrounds, and so forth. Third, all Work Area activities were concentrated in one room which limited diversity and bulk of projects. Finally, the availability of activities strongly influenced the particular tasks performed at any one time. Because the Work Area depended upon outside contracts and subcontracts from the Sheltered Workshop, there were occasional lean periods when less desirable activities were used to fill the gap.

The following is a listing of the primary activities used in the Work Area and a brief description of each:

Collating: Placing written material in its proper sequence, stapling and stacking.

These were subcontracted tasks from the Sheltered Workshop. The skills observed included direction following, following a model, numerical sequencing, motor coordination, tolerance for standing, tolerance for repetition.

Window Piece Assembly: Placing rubber strips into aluminum window pieces.

This was a subcontract job from the Sheltered Workshop. The skills required were instruction following, following a model, motor coordination, measuring ability, use of hand tools, tolerance for sitting, tolerance for repetition.

Addressograph: Using a pedal operated machine to address written material of various sizes and bulk.

This was a contract job with several Agency departments and organizations. The skills needed were eye-hand-foot coordination, dexterity, instruction following, planning and organizational ability, reading ability, perception skills.

Platemaking: Using a manually operated machine to stamp addresses on metal plates.

This was a contract job with several Agency departments and organizations and one community organization. Clients were observed on this activity for coordination, dexterity, use of written instructions, use of machinery, clerical skills, accuracy, ability to shift sets and planning and organizational ability.

Filing: Maintaining plate files of addressograph contract customers.

Files were kept alphabetically and numerically. Skills needed included verbal instruction following, numerical and alphabetical sequencing ability, planning and organizational ability, accuracy and reading ability.

Engraving: Engraving was the most complex activity performed in the Work Area. The engraving process was performed by using a Hermes cutter manually guided to produce signs in plastic material.

This involved contracts with outside organizations and individuals and total responsibility for all Center staff name tags. Other Agency engraving was also done. Skills involved included written and oral instruction following, coordination, dexterity, planning and organizational ability, size and color discrimination, use of hand tools, accuracy, ability to read, ability to shift sets, and perception skills.

Craft Items: A number of craft projects were used in the Work Area as evaluation tools. These included ceramics, rug making, decoupage, copper staining, string art, leather crafts and numerous kits of varying sizes and complexity. Most of these activities were obtained from or through the Sheltered Workshop. A vast array of skills were required. Often these tasks could be used as a practical measure of skills without the costly risk of damage to the person or equipment. These craft items were important as non-stressful time fillers for clients having occasional difficulties which prevented their functioning on more productive activities.

CLIENT:

DATE:

	Following Verbal Instructions	Following Written Instructions	Following Demonstrative Instruct.	Following a Model	Numerical Sequencing	Motor Coordination	Work Rhythm	Neatness	Planning & Organizing	Use of Machinery	Size Discrimination	Perception	Use of Hand Instruments	Tolerance for Standing	Tolerance for Sitting	Work Rate	Accuracy	Ability to Read	Tolerance for Repetition	Frustration Tolerance	Color Discrimination	Retention	Shifting Sets	Tracing a Pattern
COLLATING	X		X		X	X	X	X	X			X		X		X	X		X					
WINDOW PIECES	X		X	X		X	X		X			X	X		X	X			X			X	X	
RUG MAKING	X		X			X	X	X	X			X	X		X	X			X		X			
ADDRESSOGRAPH	X	X	X			X	X	X	X	X		X	X		X	X			X	X	X		X	
NILLY	X	X	X	X		X	X	X	X		X	X			X	X			X		X			
PLATEMAKING	X	X	X			X	X		X	X					X	X	X	X	X	X	X		X	X
DECOUPAGING	X	X	X			X	X	X	X			X	X	X		X	X	X						
COPPER STAINING	X		X			X	X	X	X			X	X		X	X					X			X
FILING	X		X		X		X		X						X	X	X	X	X					
STRING ART		X	X			X	X	X	X		X	X	X		X	X		X		X	X			
ENGRAVING	X	X	X			X	X		X	X	X	X	X		X	X	X	X		X		X	X	X
LEATHER	X		X			X	X	X	X			X	X		X	X					X		X	X

COMMENTS:

APPENDIX S

EPILEPSY CLASS CURRICULUM

COURSE I

CONTENTS:

CLASS I	Orientation
CLASS II	Evaluation
CLASS III	First Aid
CLASS IV	History of Epilepsy
CLASS V	Attitudes and Society
CLASS VI	Attitudes and Feelings about Epilepsy
CLASS VII	Psychosocial Aspects or Typical Problems
CLASS VIII	Seizures and the Brain
CLASS IX	Epilepsy: Its Causes and Treatment
CLASS X	Commonly Held Misconceptions
CLASS XI	Re-evaluation

AIMS AND GOALS OF INSTRUCTION UNITS ON EPILEPSY:

- A. To give the epileptic students in Epi-Lab factual information about their disability so they will:
1. understand the temporary nature of an epileptic seizure and its causes,
 2. understand how to properly handle a seizure and teach others to be more comfortable with them and their handicap,
 3. better understand their responsibility to comply with treatment efforts, and
 4. to be able to better advocate for themselves and be able to effectively dispel some of the misconceptions associated with epilepsy.

- B. To examine public and personal attitudes toward the epileptic person by looking at:
1. the influence of American values on societal views of the epileptic person,
 2. the psychosocial implications of epileptic seizures,
 3. personal reactions to past experiences, situations, and interpersonal interactions,
 4. responsibility for personal behavior, and
 5. the influence of attitudes on the availability and use of opportunities

CLASS I: ORIENTATION

Purpose: Motivate the students

- I. Reason for the course:
 - A. Dispel basic misconceptions
 - B. Bring about better understanding by others
 - C. Learn to effectively communicate
 - D. Gain a better understanding of oneself
- II. Skeletally outline course
 - A. Give class titles
 - B. Indicate tests to be given
 - C. Enumerate expectations
 1. Tests
 2. Homework assignments
 3. Class project
 - D. Introduction to material sources

CLASS II: EVALUATION

Purpose: Find out what information students already have in order to determine areas of need.

- I. Give Epilepsy Quiz
- II. Have students complete the Attitude Survey

Materials: Epilepsy Quiz
Attitude Survey

CLASS III: FIRST AID

Purpose: Teach students how to react appropriately if they are the victim or an observer of a seizure.

- I. Seizures are not a medical emergency
 - A. Keep calm
 - B. Observe the seizure activity
- II. WVRC Policy Sheet Handout
 - A. Go over points on the sheet
 - B. Give facts to dispel contradictions
- III. Responsibility of the person with seizures
 - A. Tell others how to help you during a seizure
 - B. Clean up after your seizure when you are able

Materials: WVRC Center Policy Statement

CLASS IV: HISTORY OF EPILEPSY

Purpose: Give students a chance to see that epilepsy has been around a long time and to see the origin of some of today's misconceptions.

- I. Give students a list of questions about the history of epilepsy
- II. Show film presentation by Dr. Withrow on the history of epilepsy
- III. Have group discussion
 - A. List of questions used as basis for discussion
 - B. Important historical figures thought to have had epilepsy

Materials: Dr. Withrow film presentation
Teacher Instruction Units on Epilepsy by the
Epilepsy Foundation of America, page 4-5
List of questions

CLASS V: ATTITUDES AND SOCIETY

Purpose: To examine student ideas of how "society" views the epileptic and the students' feelings for this "society." Secondly, we study some American values and their influence in the formation of societal views of the epileptic person.

I. Societal Views

- A. What is society's view of the epileptic?
 - 1. positive or negative
 - 2. misconception or fact
 - 3. who is society
 - 4. how do students feel society came by these feelings
- B. As a person with seizures, how do you feel about society?
 - 1. how did you come by these feelings
 - 2. is your attitude based on misconceptions
 - 3. does your view of yourself color your perception of how others see you

II. Psychosocial Implications of Epileptic Seizures

- A. Epilepsy is a hidden disability
 - 1. epilepsy is episodic
 - 2. people do not have an opportunity to adjust to the epileptic disability
- B. Seizure activity is often frightening
 - 1. seizure itself often involves alien, bizarre behavior
 - 2. observer relates strongly
- C. Seizure represents a loss of control
 - 1. perceived as such by observer
 - 2. psychologically painful to watch because person relates so strongly

III. Learned American Values Influence the Way People View the Epileptic Person

A. Major values that confront the epileptic are:

1. conformity
2. perfection
3. independence
4. competition.

B. Most epileptics cannot satisfactorily meet the demands of these values because of the nature of the disorder.

Materials: Epilepsy Rehabilitation, "The Psychosocial Aspects of Epilepsy," pp 66-72, Wright, George N., Ph.D, Ed. Boston: Little, Brown and Company, 1975.

CLASS VI: ATTITUDES AND FEELINGS ABOUT EPILEPSY

Purpose: To realistically look at the feelings and ideas one has about seizures. Secondly, using the Attitude Survey, we attempt to show the students that their attitudes toward handicapped individuals are similar to other people's attitude in that they are both positive and negative.

I. What are some of the characteristics of a "typical" seizure (grand mal)

A. List of characteristics

B. What thoughts might an uninitiated observer of these behaviors have

C. What feelings or emotions might be generated

1. negative feelings
2. postive feelings

II. Why is it important to know the thoughts and feelings involved

A. Thoughts and feelings make up attitudes which in turn effect opportunities

B. To bring about positive change, one must know various aspects of the problem.

Materials: Attitude Survey
Epilepsy Rehabilitation, "The Nature of Epilepsy," pp 18-23.

CLASS VII: PSYCHOSOCIAL ASPECTS OR TYPICAL PROBLEMS

Purpose: To provide insight into some personal problem areas other than seizure control faced by the epileptic.

I. Self image

- A. How one views himself in relation to others
- B. Each individual has worth

II. Confidence

- A. Epileptics can achieve
- B. How others see you is colored by what one presents for viewing
- C. Must be realistic and set reachable goals
- D. Do you allow people to see your disability before seeing you

III. Behavior

- A. What turns others off may not be your seizures
- B. Despite any disability, one is responsible for his behavior

Materials: Contemporary Neurology, "Psychological and Social Aspects of Epilepsy," Chapter 9.

CHAPTER VIII: SEIZURES AND THE BRAIN

Purpose: To give students factual information about their disability.

I. What is epilepsy

- A. Definition
- B. Incidence
 - 1. 4 million in U.S. have epilepsy
 - 2. one child in 50 has epilepsy
 - 3. about 100,000 new cases each year

C. Seizures as a symptom

II. What relation does the brain have to seizures

- A. The brain controls all body action

- B. It is made up of cells
 - 1. cells usually work in harmony
 - 2. seizures occur when cells become overactive and excessively discharge electrical energy
 - 3. this is sometimes localized or sometimes generalized
- C. Of the 10 billion nerve cells in the brain, only 7 must malfunction to cause a seizure

III. Seizure types

- A. Seizures are not necessarily equivalent to epilepsy
 - 1. may result from low blood sugar
 - 2. considered epilepsy when frequent and re-occurring
 - 3. seizures are major symptom of epilepsy
- B. Seizures classified by International Classification System
 - 1. divided into two main groups - partial and generalized
 - 2. according to area of brain affected
- C. Three major types
 - 1. petit mal or absence
 - a. periods of altered consciousness
 - b. 5 to 30 seconds
 - c. staring; rhythmic movements of facial muscles, head or arms
 - 2. grand mal (tonic-clonic)
 - a. description
 - b. lasts 2-3 minutes
 - c. causes greatest problems vocationally
 - 3. psychomotor seizures
 - a. state of awareness is affected

- b. may perform purposeless motions called automatisms
- c. lasts several minutes to several hours
- d. involves temporal lobe which affects the senses-sight, smell, etc., and emotions
- D. Most people have one type of epilepsy but may have two or more
- E. Epileptic attacks tend to be similar on different occasions
- F. Epileptic attacks involve some form of stereotyped, repetitive and purposeless behavior

Material: Teacher's Instruction Unit, pp 10-12.
 The Epilepsy Fact Book, pp 1-5, Sands, Harry and Frances C. Minters. Philadelphia: F. A. Davis Company, 1977.
Epilepsy Rehabilitation, "The Nature of Epilepsy," pp 16-24, and 31.

CLASS IX: EPILEPSY: ITS CAUSES AND TREATMENT

Purpose: To further enhance the knowledge these people have about their disability and enhance self-image by shattering some of the ill-conceived notions about the origin of their disability. Plus, we wish to impress upon the students their responsibility for compliance with treatment.

I. What causes epilepsy

- A. Idiopathic (cause unknown) cases "just appear" with no evident precipitating cause
- B. Symptomatic (cause known) causes are many
 - 1. Congenital, Natal, and Perinatal Factors
 - a. congenital abnormalities of the brain
 - 1. too many or too few chromosomes
 - 2. drugs or radiation
 - 3. diseases
 - b. maternal infections-syphilis or German measles
 - c. perinatal or birth causes
 - 1. birth trauma

2. inadequate oxygen to the brain
3. blood sugar
4. blood incompatibility with jaundice

2. Infection

- a. of the nervous system
- b. encephalitis or meningitis

3. Toxic causes

- a. alcohol and lead poisoning
- b. interferes with normal equilibrium of the nervous system

4. Head injuries

- a. frequently result in post-traumatic seizures
- b. auto accidents, sports injuries, war wounds, etc.

5. Brain tumors

- a. accounts for 10% of adult-onset cases of epilepsy
- b. usually focal and can help locate the seizure

C. All cases of epilepsy involve some injury to the brain.

II. What are the major types of treatments for epilepsy?

A. Epilepsy cannot be cured

1. it can be controlled in most instances
2. some children do outgrow the condition

B. Anti-convulsant drugs is the usual treatment

1. by this method 50% get full control
2. 30% get partial control
3. most people require combination of drugs for maximum control
4. most drugs are effective with only certain types of seizures
5. accurate diagnosis critical to maximum control

6. ideal dosage stops seizures with a minimum of side effects
 7. dosage must allow for functioning
 8. medication compliance is essential
 9. adequate blood levels of medication must be maintained for treatment to work
- C. Surgery is an alternative treatment
1. effective only in small number of cases
 2. only possible when specific cause is known
 3. used when it will not cause more extensive damage to brain
- D. Emotional adjustment is critical to the seizure person
1. must learn to live with his disorder
 2. must attempt to control fatigue, emotional tension, and stress.

Materials: Epilepsy Rehabilitation, "Medical Considerations," pp 34-45.

CLASS X: COMMONLY HELD MISCONCEPTIONS

Purpose: Epileptic clients need factual rebuttals for the misconceptions believed by themselves and the public.

- I. Seizures may be conditioned responses
 - A. Learned means of handling stressful situations
 - B. The seizure threshold builds to the point that seizure activity is triggered
 - C. Known triggers may be used to bring about gratification
- II. Epilepsy is not inherited
 - A. What makes the difference may be persons seizure threshold
 1. this is the susceptibility of each person's brain to the development of seizures
 2. research indicates that the interaction between heredity and environment is responsible, especially in symptomatic epilepsy.

- III. Epilepsy is not linked with insanity or mental retardation
 - A. Injury to the brain which causes epilepsy may cause mental retardation or cerebral palsy
 - B. Injury to the brain which causes epilepsy may cause other learning difficulties
- IV. Epilepsy does not worsen with age
 - A. Some persons experience fewer seizures later in life
 - B. Under doctor's guidance and careful supervision 47 to 92% of children stop having seizures by adolescence.
- V. Many misconceptions about a seizure itself
 - A. Seizure is not a medical emergency
 - B. A person cannot swallow his tongue
 - C. Seizures are self-limiting
 - D. One cannot stop a seizure once it has begun
 - E. Seizure victim does not suffer during a seizure
 - F. Epilepsy is not contagious, but the initial cause may be
- VI. There are steps we can take to prevent epilepsy
 - A. Get proper medical care in pregnancy and childbirth
 - B. Decrease chance of brain injury before, during, and after birth
 - C. Prevention of infectious diseases eliminates a source of epilepsy
 - D. Good nutrition plays a part in epilepsy prevention
 - E. Prevent serious head injuries
 - 1. use helmets
 - 2. take necessary precautions
- VII. Epileptic person can get driver's license if certified by a doctor to be under adequate control for a specific period of time.
 - A. Must be seizure free 2 years in West Virginia

- B. On denial or revocation of license, person is entitled to a hearing
 - C. Those properly licensed with adequate medical supervision have fewer auto accidents than non-handicapped groups.
- VIII. Handicapped workers, including epileptics, properly placed in jobs are less subject to injury and days lost due to illness than are unaffected groups.
- A. Patient with uncontrolled seizures with other neurological disturbances can rarely be placed in usual occupations
 - B. Realistic appraisal of person's potential must be considered based upon individual problems and background
 - C. Many with convulsive disorders do have poor work records and poor preparation for independent adult life
 - D. The epileptic person's measure of opportunity to enter an occupation depends upon individual abilities, motivation, nature and severity of the seizure disorder
 - E. Studies show social adaptive abilities appear to be at least as important in determining employability as does seizure control
- IX. There is no reason to exclude the child who is well controlled and has normal intellectual capabilities from regular school classes or normal activities.
- A. Too stringent restrictions can be as dangerous to normal emotional development as is physical injury
 - B. Properly handled, occasional seizure need not be disruptive and could be educational experience for other children
- X. Life Insurance
- A. Before the epileptic had to pay more or accept substandard policies
 - B. Now, there is a national group life insurance policy through the Epilepsy Foundation of America specifically to include epileptics
- XI. Health Insurance hard to get with private companies
- A. Try group plan

B. Group plan inexpensive

C. Coverage automatic to all members under group plan

Materials: Contemporary Neurology, "Psychosocial and Social Aspects of Epilepsy," Chapter 9
Epilepsy Fact Book, pg 17
Presentation to Marshall University Driver's Education Class by David Steurer on June 11, 1976.

CLASS XI: RE-EVALUATION

Purpose: Retest to assess effectiveness of class and readiness for Course II.

A. Give Epilepsy Quiz

B. Introduce Course II

Materials: Epilepsy Quiz

APPENDIX T
RANKING OF CLIENT SCORES
ON EPILEPSY QUIZ

<u>CLIENT</u>	<u>QUIZ SCORE</u>	<u>PERCENT</u>
8	46	90%
14	46	90%
21	44	86%
15	42	82%
11	39	76%
9	38	75%
17	38	75%
10	37	73%
4	36	71%
2	36	71%
12	36	71%
23	36	71%
7	35	69%
13	35	69%
20	35	69%
26	34	67%
19	33	65%
24	33	65%
25	33	65%
27	29	57%
16	26	51%
22	26	51%
6	25	49%
3	23	45%

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APPENDIX U

STUDENT SURVEY EVALUATION QUESTIONNAIRE

The following information is a presentation and analysis of a questionnaire sent to all students served in Epi-Lab after the program terminated in April 1979. The intent of the questionnaire was to seek feedback and comments in regard to the impressions of the program, recommendations and criticisms from the persons who were served in Epi-Lab.

The analysis of this questionnaire must take into consideration that only 57% of the 28 clients served responded to the questionnaire. It is probable that those clients that did respond were the ones who were most favorably impressed with the program. It is known that many of the clients who had negative or unfortunate experiences in Epi-Lab did not respond, but it might be presumed that their responses would be mostly negative. Keeping these considerations in mind, the following discussion will be based upon the information received from the 16 clients who did return the questionnaire.

STUDENT SURVEY EVALUATION QUESTIONNAIRE

Total Sent 28

Total Returned 16 - 57%

1. Did Epi-Lab help you better understand your epilepsy:

	No.	%
Yes	14	86
No	2	13

2. What parts of Epi-Lab helped you *the most*? (Check 1 or more)

	No.	%		No.	%
Group	11	69	Classes	6	38
Work Area	9	56	OT	1	6
Recreation	2	13	Medical	5	31
Counseling	2	13			

3. What parts of Epi-Lab helped you *the least*? (Check 1 or more)

	No.	%		No.	%
Group	2	13	Classes	0	
Work Area	1	6	OT	4	25
Recreation	6	38	Medical	2	13
Counseling	2	13			

4. Would you recommend Epi-Lab to a friend who has epilepsy?

	No.	%
Yes	12	75
No	3	19
Did Not Answer	1	6

5. How did you benefit from Epi-Lab? (Check all that apply)

	No.	%
Better seizure control	8	50
Understand myself better	9	56
More confident	9	59
Feel better about myself	8	50
Can make decisions on my own	7	44
Better able to get along with others	8	50
Worry less about my seizures	11	69
Better able to recognize and use my abilities	7	44
Less dependent upon others (parents, spouse, etc.)	5	31

6. Do you think Epi-Lab should be continued by the Rehabilitation Center? (check one)

	No.	%
Yes	11	69
No	4	25
Did Not Answer	1	6

If yes, how? (check one)

	No.	%
Keep as a separate program	3	19
Use Epi-Lab ideas (groups, classes, etc.) in other program areas (workshop, training, etc.)	8	50
Did Not Answer	5	31

If yes, why?

I would personally benefit	1	6
Other students would benefit	9	56
Both	2	13
Did Not Answer	4	25

STUDENT SURVEY COMMENTS:

In response to the question, "Would you recommend Epi-Lab to a friend who has epilepsy?" the following reasons for answering yes or no were given:

1. "To help them understand their problems"
2. "Help understanding self better"
3. "Help to know more about epilepsy"

4. "To provide opportunity for sharing with others with the same disorder and problems...Learning to understand and cope with these problems - it is hard to do it alone."
5. "To learn to be more independent and confident."
6. "Because it helped me and I was almost totally convinced I was beyond help."
7. "It depends on the person."

In response to question #7, "Do you have any suggestions or ideas about how Epi-Lab could be improved," the following comments were offered:

1. "Make classes and/or groups available to other epileptic clients at the Center."
2. "Have programs for persons who are living in the community."
3. "Give the person more time to adjust to his disability."
4. "Do testing prior to entry."
5. "It helped me the way it was so I would be afraid to change it, but everything has room for improvement."

In response to the question, "Do you have any comments about how programs and services to people with epilepsy throughout the Rehabilitation Center could be improved," the following comments were offered:

1. "Have more epilepsy center programs."
2. "Have client learn as much about epilepsy as he can."
3. "Don't get excited when a seizure occurs; do not overly restrict the person with epilepsy."

ADDITIONAL COMMENTS:

Several students made additional comments on the questionnaire. They are as follows:

1. "My mother made a comment that she was very glad our government came up with such a program as Epi-Lab because, something, the program, finally made me do something with my life."
2. "The money should be appropriated to the epileptic just the same as any other handicap such as polio, th., birth defects, etc., and used wisely and by people really interested in the epileptic."

APPENDIX V

STAFF PROJECT EVALUATION QUESTIONNAIRE

For the purpose of evaluating the impact of the Epilepsy Project upon the staff at the Rehabilitation Center and the Agency, a questionnaire was designed and mailed to selected staff. In spite of a poor return percentage (43%), many valuable ideas and important feedback was received from those that did respond. The following is an analysis and discussion of the results of this questionnaire.

NUMBER SENT: 195

NUMBER RETURNED: 83 - 43%

RECEIVED FROM:

<u>GROUP</u>	<u>NUMBER</u>	
1	27	Center staff who worked directly with Project clients.
2	15	Center staff who did not work directly with Project clients.
3	15	Field counselors who referred clients to Epi-Lab.
4	19	Administrative, management in Center, field, and State Office.
5	7	Other staff

N=83

QUESTION 2

During the Epi-Lab Project period (Nov 1, 1977-April 7, 1979), and as a result of Project activities, did your understanding and awareness of epilepsy and the problems, concerns, etc. of the person with epilepsy increase? How?

<u>GROUP</u>	<u>1</u>		<u>2</u>		<u>3</u>		<u>4</u>		<u>5</u>		<u>Total</u>	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	23	85	12	80	10	67	16	84	3	43	64	77
No	4	14	3	18	4	27	3	16	4	57	18	22
Not Sure	-		-		1	6	-		-		1	1

Twenty-seven Center staff who worked directly with Project clients (Group 1) responded to the questionnaire. Most of them (85%) derived some benefit from the Project in their ability to work with epileptic clients. Their comments suggested that the major impact was in:

1. informing them of the correct procedure for handling a seizure,
2. educating them as to the many types of seizures,
3. increasing their awareness of the psychological, behavioral, perceptual, judgement and communications problems that are often not readily noticed but have definite impact upon the person's functioning,
4. increasing their awareness of public and professional attitudes concerning employment issues, and
5. improving their overall awareness of the problems surrounding epilepsy.

Comments by Group 3 (field counselors) included:

1. increased awareness of the difficulty in case management when the epileptic condition is associated with other conditions such as autism, long dependency, parents and/or boyfriend problems,
2. increased awareness of the problems faced by the epileptic, especially the psychological problems, and
3. increased knowledge of the various treatments for all problems associated with epilepsy.

Comments by Group 4 (Administrative staff) included:

1. realizing that the problem that the epileptic faces in securing employment is far more complex than the mere control of his seizures,
2. acknowledging that behavioral and learning disorders not previously understood may very well be the most difficult part of the Rehabilitation problem,
3. improving overall awareness of the problems of the persons with seizures,
4. recognizing the need for better and more complete services and better resources for epilepsy,
5. recognizing the need for staff training in the area of epilepsy, and

6. increasing awareness of the overall problems.

Group 5 comments to this question included:

1. increased awareness of how social problems can be overcome and how self-improvement takes place when someone cares,
2. knowledge of epilepsy in general, particularly in regard to periodic falls which damages the teeth and surrounding tissue,
3. increasing awareness of additional problems of hyperplasia of the peridontal tissues from Dilantin, and
4. increased awareness of the effects of sedative medication on personality and disposition of some clients.

QUESTION 3

From your perspective, did the clients you know that were served by the Epilepsy Project improve as a result of Project services?

GROUP	1		2		3		4		5		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	17	63	4	27	4	27	8	42	1	14	34	41
No	2	7	1	6	5	33	1	5	0		9	11
No Opportunity to be Aware of Change	8	30	9	60	6	40	10	53	6	86	39	47
Yes and No	-		1	6	-		-		-		1	1
If yes, how?												
Better Seizure Control	11	41	4	26	3	20	5	26	-		23	
Improvement in Behavior	15	55	5	33	3	20	5	26	1	14	29	
More Independent	16	59	5	33	3	20	3	16	1	14	28	
Better Social and Interpersonal Skills	14	52	5	33	3	20	5	26	1	14	28	
Better Able to Cope	11	41	5	33	3	20	6	32	-		25	
Improved Appearance and Presentation	15	55	2	13	2	13	4	21	1	14	24	
Less Handicapped by Epilepsy	11	41	4	27	3	20	5	26	-		23	

Improved Self-image	1	4	-	-	-	-	1
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If no, in what areas was improvement not evident?

Seizure Control	2	7	-	3	20	-	-	5
Behavior	2	7	2	13	3	20	1	5
Social and Interpersonal Skills	2	7	-	5	33	-	-	7
Coping Ability	1	4	2	13	2	20	-	5
Appearance and Presentation of Self	-	-	-	2	20	-	-	2

Client improvement has, of course, been difficult to measure. Various efforts, including the rating scale, observations, and psychometrics have produced varying results. Another method of ascertaining client change was asking staff in all five groups for their impressions of client change. The analysis of question 3 answers this question.

Overall, thirty-four or 41% of all staff answering this questionnaire believed there was some client change as a result of Project services. The group that should have been most aware of client change, Group 1, strongly felt (63%) that clients did change.

It is noted, however, that 47% of the staff group was not in a position to be aware of client change.

When asked in what areas change was most evident, most staff felt that 'improvement in behavior', 'independence', 'social and interpersonal skills', and 'coping ability' were the most significant.

QUESTION 4

Should Epi-Lab be continued?

GROUP	1		2		3		4		5		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	20	75	9	60	14	93	18	95	5	71	66	80
No	3	11	1	7	-	-	-	-	-	-	4	5
Did Not Answer	4	15	5	33	1	7	1	5	2	29	13	15
If Yes, in what form?												
Maintain as Separate Unit	4	15	0	-	7	47	2	11	1	14	14	17

Incorporate Successful Components into Existing Center Programs	16	59	9	60	7	47	17	89	4	57	53	64
Do Both	-	-	-	-	1	7	-	-	-	-	1	1
Did Not Answer	7	26	6	40	-	-	-	-	2	29	15	18

The great majority of the staff responding to this questionnaire felt that Epi-Lab should be continued (80%). The majority (64%) felt that the successful components of Epi-Lab should be incorporated into existing Center programs, as opposed to maintaining the unit as a separate entity. It is significant that only 5% of the staff did not recommend continuation in some form.

QUESTION 5

Did the Epilepsy Project assist you in performing those job duties (program planning, counseling, teaching, job placement, nursing, etc.) that impact upon clients with epilepsy more effectively?

GROUP	1		2		3		4		5		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Yes	16	59	5	33	7	47	10	53	1	14	39	47
No	4	15	5	33	5	33	3	16	3	43	20	24
Did Not Answer	7	26	5	33	3	20	6	32	3	43	24	29

This question was intended to measure the staff's impression of the assistance that the Project had been either directly or indirectly in assisting them in performing their job function, whatever it might be. The most significant impact seemed to have been in Groups 1 and 4, which would be expected. Almost half of the field counselors responding believed that the Project made some impact upon their job duties also.

In Group 1, some of the positive comments by those who thought that the program did help them in performing their job included:

1. "given me a better insight into program planning concerning classroom teaching,"
2. "given me a better understanding of the person with epilepsy,"
3. "a realization of the need for good counselor-teacher communications, as well as background information on students,"

4. "an awareness that the clients of Epi-Lab were generally more willing to accept ideas outside their own experience which facilitated working with them,"
5. "an increased sensitivity or tolerance to cycles of intelligence and ability contrasted with periods of slowness and dullness in students with epilepsy,"
6. "improved knowledge in handling the manipulative behavioral aspects of seizure episodes in a medical treatment setting,"
7. "increased awareness of how epilepsy should be handled in the dormitories by making me more aware of the adjustment problems and obstacles of the persons with this disability,"
8. "improved ability to counsel with the epileptic client and evaluate his Rehabilitation potential,"
9. "made me more knowledgeable concerning what to expect from clients, thus better prepared to respond to client needs in an appropriate fashion," and
10. "increasing awareness of job placement issues in placing persons with epilepsy on jobs."

Comments from Group 2 included: "improved understanding of epilepsy."

Comments from Group 3 included:

1. "increased awareness of client limitations,"
2. "recognizing the need for more staff training,"
3. "better able to counsel clients and parents and plan programs for people with epilepsy,"
4. "assisting me in coping with the problems of persons with epilepsy that I encounter in my job,"
5. "better understanding of the relationship between seizure control and behavior improvement," and
6. "given me more insight into my clients with epilepsy."

Group 4 comments included:

1. "improved ability to plan for in-service training for Center client serving personnel,"
2. "improving my ability to consider the needs of this disability group in supervising and planning for client service elements of the Agency program,"

3. "making me feel more comfortable in speaking about serving the severely disabled to clients and counselors alike," and
4. "making me aware of those services necessary to serve this population."

QUESTION 6

In your opinion, what part of Epi-Lab was most effective in bringing about client change or improvement? (please rank in order of effectiveness, 1= most effective)

	Group 1	Group 2	Group 3	Group 4	Group 5	Total
Group	2	1	2	1		1
Work Area	3	5	5	2		4
Recreation	5	6	6	5		6
Individual Counseling	1	2	3	3		2
Epilepsy Classes	4	4	1	4		3
Occupational Therapy	7	7	7	8		7
Speech Therapy	8	8	8	7		8
Medical Treatment	6	3	4	6		5

The above table represents the average rankings by group in terms of the staff's impression of the effectiveness of various components of Epi-Lab. From the above rankings, it would appear that in the opinion of the staff the most effective components were Group Therapy, Individual Counseling, Epilepsy Class and the Work Area. Of course, it must be considered that each group had different levels of awareness of the details of program functioning and client benefit. It is interesting that the two groups who probably had the most knowledge of the details of the program had similar rankings, while the rankings of Groups 2 and 3, which had the least knowledge of program details, had similar rankings.

QUESTION 7

Do you have any suggestions as to how Epi-Lab or services to persons with epilepsy at WVRG could be improved.

In response to question 7, the following comments were made by Group 1:

1. "All persons with epilepsy should have follow-up in the Neuro clinic."
2. "Services to persons with epilepsy could be improved by intensive investigation of the problem of learning difficulties in this population. Additionally, solutions for correcting aggressive, hostile, acting-out is necessary for continued work with some of these clients in the Center setting."
3. "More in-service education of medical personnel is needed."
4. "Just continue on."
5. "Increase infiltration of these clients and the respective components into the Center program."
6. "Intervention in learning disabilities of the client with epilepsy."
7. "Make Epi-Lab services available to all clients with epilepsy at the Center."
8. "Increased neurological time."
9. "Utilization of full-time LD person."

Group 2 offered the following comments to question 7:

1. "De-emphasize "specialness" of the epileptic."
2. "Structure more group therapy with all disability groups."
3. "Continue epilepsy class."

Group 3 made the following comments in addition to those made by Groups 1 and 2:

1. "The team approach was an enviable asset. The frequent consultations with the neurologist, psychiatrist, and psychologist could greatly help the counselor in his close work with all clients at the Center."
2. "Don't discontinue Epi-Lab. This is a very needed program. At least have a special counselor with availability of group and individual therapy."
3. "Expand the program to include persons with multiple disabilities as well as epilepsy."

Group 4 offered additional comments, including:

1. "Attempt to maintain the gains made during the tenure of Epi-Lab."

2. "Increase public education; maintain any services that will continue to provide the education and support to epilepsy clients that were part of the Project."
3. "Continue education of Center staff regarding treatment of epileptic clients."
4. "Make report of major findings and recommendations available to districts to encourage field counselors to work with epileptic clients."

Group 5 made some comments concerning:

1. The need for rehabilitation services should not be based entirely upon epilepsy, but rather a need for other services in addition to the fact the client is epileptic.

QUESTION 8

Do you have other suggestions, criticisms or opinions regarding Project activities?

Group 1 made the following suggestions, criticisms or opinions.

1. "The Project limited itself too severely as far as acceptance of clients."
2. "Neurological treatment should stabilize medical problems as much as possible before Center entry so the Rehabilitation Center could concentrate more upon problems of vocational evaluation and training."
3. "I don't see why it has to be closed down, for if only one person has been helped, then it has been worth everyone's effort and cost."
4. "Better medical records should be kept so that more knowledge could be obtained on the medical aspects of this population. Part-time medical assistance caused problems in implementing new programs such as drug levels, as well as in readjusting medications when seizure activity occurred."
5. "More effort is needed in the areas of job placement and employment for this population."
6. "The Center needs a reliable, effective way of evaluating vocational potential of epileptic clients with brain damage. Existing evaluation systems are insufficient. The professional expertise necessary should be made available at the Center for this most frequent problem."

7. "The first two meetings sounded somewhat encouraging. There would be a psychiatrist and psychologist and it would be a separate unit. After a couple of weeks, I never saw the people from CAMC. Dr. Withrow's time was taken up almost completely by Epi-Lab clients and had little time to see routine neurological problems. Many lacerations were repaired in medical clinic and I think all sutures removed. Clients were brought to the medical clinic on stretchers habitually and I understood at indoctrination they would be "left where they fell" until somewhat alert. Sour Grapes!"
8. "More emphasis should be made in presentations and education of the general public."
9. "Goals of the program should be clarified for staff."
10. The Center neurologist stated, "A good program that has shown definite potential to improve seizure control and emotional adjustment problems of the epileptic clients."
11. "A more comprehensive client contact staff training is needed."

Group 3 offered the following suggestions, criticisms or opinions in addition to those offered by Group 1:

1. "Center personnel should be more aware of limitations of field services and make greater efforts to work with difficult problems of severely disabled clients. The Center should be able, with all of its professional staff, to accomplish more in this area than the field."
2. "I feel that the Screening Committee was too selective."
3. "I would like to see the Project serve more individuals with lower IQ's."
4. "This was, in my estimation, the most worthwhile Project ever under Agency sponsorship. I have many clients in Epi-Lab; if one is rehabilitated it was worth everything. Due to past history, it is hard for me to believe this Project is not going to continue."

Group 4 offered the following in response to question 8:

1. "The Project should concentrate on more feasible cases."
2. "We didn't find the way to identify candidates for these services. Perhaps we might try some kind of vigorous effort of setting up a register in conjunction with the schools and special education to get in touch with the possible candidates as they approach work age."
3. "Training at the local offices could and should enhance

the program. As successful as the program was, I didn't feel many counselors knew the benefits of the use of the program."

Group 5 made additional comments:

1. "Presentations by Project staff to Secretarial Workshops were helpful and valuable information was passed on to clericals who often have to deal with seizure clients. They indicated that they felt more confident and capable of dealing with this disability group after these presentations."

APPENDIX W

EPI-LAB ADVISORY GROUP COMPOSITION

The membership of the Advisory Group comprised representatives from all aspects of society which are involved with epilepsy. They included the following:

1. Mr. George Bennett, Director, Developmental Disabilities Planning Council,
2. Mrs. Connie Bishop, R. N., Division of Crippled Children's Services, W. Va. Department of Welfare,
3. Dr. Allen Blumberg, Director of Special Education, W. Va. College of Graduate Studies,
4. Mrs. Gloria Chewning, Mountain State Epilepsy League; parent,
5. Mr. Thomas Long, Curriculum Development Specialist for the Physically Handicapped, W. Va. Department of Education,
6. Mrs. Betty Rivard, Social Worker, Division of Social Services, W. Va. Department of Welfare,
7. Dr. William Svoboda, Pediatric Neurologist, W. Va. University Medical Center; President, Mountain State Epilepsy League,
8. Mr. Richard Vincent, Division of Community Services, W. Va. Department of Health, and
9. Mr. Earl W. Wolfe, Executive Assistant Director, W. Va. Division of Vocational Rehabilitation.

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